

**UNDERSTANDING SEXUALITY OF PERSONS WITH DISABILITY IN  
RESIDENTIAL FACILITIES IN GAUTENG, SOUTH AFRICA:  
PERCEPTIONS OF SERVICE PROVIDERS AND PEOPLE WITH  
DISABILITIES.**

**BY**

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**Submitted in fulfilment  
of the requirement for the degree of  
Master of Social Work at the  
University of KwaZulu-Natal  
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**UNIVERSITY OF KWAZULU-NATAL**

**2017**

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## **ABSTRACT**

This study explored the realities of people with disabilities living in institutions in Gauteng, South Africa. The study focused on perspectives of service providers and people with disabilities. There is limited research on sexuality and disability from a South African perspective, which this study aimed to redress.

The goal of the study was to explore sexuality as a form of pleasure and expression of love, for people with disabilities via qualitative research. Anti-Oppressive theory was the framework used to provide a broader understanding of sexuality and disability. The target sample was from residential facilities in Gauteng. In-depth interviews were used for people with disabilities and focus groups with service providers.

This study found that the sexuality of people with disabilities was not prioritised with results uncovering: lack of privacy, lack of training and provision of sexual health education programs, denial of intimate relationships, negative self-esteem, unpleasant sexual experiences (abuse). Other concerns were, the nonexistence of sexuality policies, infantilisation of adults with disabilities, and negative attitudes towards the sexuality of people with disabilities. The recommendations were mainly: disability sensitisation and awareness campaigns at structural and residential care level.

## **DECLARATION ON PLAGARISM**

I, Tapiwa Antoinette Muswera, hereby declare that this thesis for the Master of Social Work degree at the University of KwaZulu-Natal, hereby submitted by me has not previously been submitted for a degree at this or other institution and it is my own work in design and execution. All reference materials contained therein have been duly acknowledged.

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**SIGNATURE**

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**DATE**

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## **ABBREVIATIONS AND ACRONYMS**

AAIDD	American Association on Intellectual and Developmental Disabilities
AIDS	Acquired Immune Deficiency Syndrome
AOP	Anti-Oppressive Practice
DPSA	Disabled People South Africa
IDD	Intellectual Development Disorder
INDS	Integrated National Disability Strategy
IQ	Intelligence Quotient
HIV	Human Immune Virus
NSW	New South Wales
Stats SA	Statistics South Africa
STIs	Sexually Transmitted Infections
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations International Children Emergency Fund
WHO	World Health Organisation
WPRPD	White Paper on the Rights of Persons with Disabilities

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## **ACKNOWLEDGEMENTS**

It is my pleasure to acknowledge the roles of individuals who were instrumental for the completion of my study.

I would like to thank the Lord for giving me the grace, strength and wisdom for in Him I live, move and have my being.

To my supervisor Professor M. I Kasiram, who held my hand throughout the journey. Thank you for your patience, tremendous support and guidance. It was a great honour to work under your supervision.

My co-supervisor Doctor D. Holscher, thank you for facilitating my work and for your benevolence. You and the entire team from the Department of Social Work at the University of KwaZulu-Natal made it possible to complete this study.

I am grateful to my family, Mr. P and Mrs. G Muswera, who have supported me financially and emotionally to pursue my dreams. My sister, Nyasha Muswera and family, thank you for your unflagging encouragement.

To Paul Chappell and Rosalie Powers thank you for your expertise and contributions to my study and for paving way for future research in the disability field.

To my friends Adriana, Maxine, Faffy and Fortune, thank you for waking me up and proof reading my work.

My interpreter and friend, Busi Caciso, thank you for your input and support.

To all my participants who shared their experiences and allowed me into their world, thank you for your time and contributions into my study.

## **DEDICATION**

This study is dedicated to all people with disabilities. May you enjoy life to the fullest; may your voices be heard everywhere you are.

## **CHAPTER 1: INTRODUCTION**

### **1.1 INTRODUCTION**

Perceptions of sexuality of people with disabilities are primarily negative and yet sexuality is a key part of human nature. Unfortunately for people with disabilities it is viewed differently from able-bodied people. Tepper (2000) asserts that sexuality is a form of pleasure and expression of love is considered as strange and unacceptable for persons with disability. The purpose of this study is to understand the sexuality of people with disabilities in institutions from the perspectives of both the service providers and the people with disabilities in South Africa with Gauteng Province as a case study. This study aims to identify the practical challenges faced by people with disabilities in the area of sexuality and attempts to recommend possible solutions in order for people with disabilities to enjoy their sexuality even though they are institutions in the same fashion like able-bodied persons.

To this end, this chapter broadly introduces the various aspects concerning the sexuality of people with disabilities and it proceeds as follows: the background and motivation of the study; the significance of the study; the research objectives; the theoretical frameworks; the research methodology; the definitions of key terms; the ethical considerations; the limitations of the study and the chapter outline.

### **1.2 BACKGROUND AND MOTIVATION OF THE STUDY**

This research was motivated by a number problems faced by people with disabilities who are institutionalised in that either they do not freely exercise their sexuality or they have very limited and often non-private ways of exercising their sexuality. Literature suggests that people with disabilities' sexuality is repressed and overt sexual expressions lead to detrimental consequences notably labelling and punishment. People with disabilities are generally portrayed as abnormal and freaks of nature (Anderson & Kitchin, 2000). In addition, there are stereotypes and myths associated with people with disabilities that different societies frown upon which affects the sexuality of people with disabilities that this study aims to decode. This is part of the problem identified which this study seeks to answer. A problem statement according to Carmichael (2009) is the representation of a subject or concern currently existing

which needs to be addressed. It also provides the context of the research study and generates the questions which the research aims to answer.

One of the concerns that exacerbates the problem of sexuality for people with disabilities is the extent to which information on sexual health is accessible. It has been observed that accessibility to sexual health education is limited, for example, due to lack and/ or limited access to resources (Gomez, 2012). This has adversely resulted in a number of crimes committed against people with disabilities (United Nations International Children's Emergency Fund, 2006). Research has shown that people with disabilities, particularly women, are more prone to abuse because of mobility issues, communication barriers and isolation (Bryen & Bornman, 2014). Conservative estimates suggest that 50% of women with intellectual disabilities are sexually abused within their life time (Szollos & McCabe, 1995 in Meaney-Tavares; Gavindia-Payne, 2012). The World Health Organisation (WHO) estimates that 10% of the global population, that is, 450 million adults with disabilities and 200 million children with disabilities experience some form violence against them than their non-disabled peers.

In light of the above, this study seeks to explore the gaps in literature within the South African context, in terms of policies, particularly those pertaining to the sexuality of people with disabilities. One observes that, people with disabilities are commonly understood to be either asexual or oversexed hence this study aims to investigate whether these are claims true and if so to what extent they affect the sexuality of people with disabilities.

In order to address the main aim of this study which is to understand the sexuality of persons with disability living in institutions. This study was conducted using two sets of participants namely, people with disabilities as well as their service providers. Further, this study was conducted at the chosen residential institutions. Key to the investigations regarding the sexuality of people with disabilities living in institutions was the extent to which their sexual rights were being protected. In addition, it was also important to investigate how institutions handle sexual expression of their service users. Furthermore, there was need to investigate whether there are any policies in South Africa that address the sexuality of persons with disability particularly those living in institutions.

### **1.3 SIGNIFICANCE OF THE STUDY**

According to Abramson, Parker and Weisber (1988) sexuality has always been an area fraught with misinterpretation and moral dispute, adding that disability provides an added twist. Perceptions towards the sexuality of individuals with disabilities have been examined from a number of perspectives. Research has revealed that developed countries such as Britain, the United States of America and Australia have considered the attitudes of parents and disability support workers or caregivers in institutions, to have become more positive over the years, towards the sexuality of people with disabilities (Cuskelly & Bryde, 2004).

Sexuality in the African context is a subject that connotes discomfort when it comes to religious and cultural paradigms and if it is to be discussed at all, it is done in whispers (Samowitz, 2009). Sexuality in this study is the quality of being sexual, engaging in sexual activity and the decision to engage in sexuality (UNICEF, 2002). People with disabilities seem to be perceived as ill or tragic victims and as a result, negative attitudes are continually reinforced (Samowitz, 2009). It is therefore unquestionable that disability and sexuality is an important area of concern in South Africa and the need to demystify and unveil these perceptions on this subject is vital. Prevailing societal values over the years, issues of human sexuality, sexual health education and sexuality counselling have been avoided for people with disabilities (Shakespeare, 2000). This has resulted in people with disabilities being deprived of or limited in their friendships, relationships and/or a sexual life (Shutterworth & Mona, 2002).

Developmental disabilities are also referred to as intellectual or cognitive impairments in this study. Such persons are obstructed by societal barriers from developing romantic or intimate relationships and are discouraged from any sexual expression (Saxe & Flanagan, 2014). Anderson and Kitchin (2000) argue that women with disabilities go through forced sterilisation and in most cases, they do not know why they go through it, which was an area of concern that needs further attention as will be shown in this study. Statistical comparisons in data between 1997-1999 and 2000-2002 reflected an increase of 78% in reports of physical and sexual abuse of women and children with disabilities (UNICEF, 2006). Furthermore, research shows that women with intellectual disabilities are even more vulnerable to sexual abuse, as they are likely not to resist and if they report the abuse, they are less likely to be believed (Sullivan, 2000). People with intellectual disability experience higher rates of sexual abuse than able bodied people (Furey, 1994) including numerous sexually abusive cases (Sobsey & Doe, 1991). Morrison (2006) notes that women are more prone to sexual assault than men whether they



have a disability or not. This is a worrying trend that will be explored in the study. Additionally, international studies have estimated that more than 70% of women with disabilities have been violently assaulted at some point in their lives (WHO, 2010). Sexual abuse is awfully common in people with intellectual disability (Carmody, 1991; McCarthy & Thompson, 1997). Consequently, people with intellectual disability are exposed to sexually transmitted diseases, HIV and AIDS (Department of Social Development, 2010) and also negative attitudes towards their own sexuality (Saxe & Flanagan, 2014). The search for literature on perceptions of sexuality in South Africa has yielded little result as most research is concentrated from a west-centric, socio-medical perspective and has tended to focus on men with acquired disabilities (Chappell, 2013). Therefore, this study is quite pertinent in order to generate debate and knowledge in this less researched yet extremely valuable component of the South African social fabric.

## **1.4 RESEARCH AIM AND OBJECTIVES**

### **1.4.1 Research Aim**

The underlying aim of this study is to understand the sexuality of people with disabilities living in institutions, from the perspective of service providers and the affected persons with disability with the intention of proposing practical solutions.

### **1.4.2 Research Objectives**

The term objective deals with the means or steps taken to reach the end goal (De Vos, Strydom & Delport, 2005), therefore, the objectives of this study are:

- a) To establish what policies exist on sexuality in institutions;
- b) To explore perceptions about the sexuality of people with disabilities from the perspective of service providers;
- c) To gain insight on how people with disabilities in institutions perceive their sexuality;
- d) To explore challenges people with disabilities face when it comes to expressing their sexuality;
- e) To explore service providers' understanding of sex education for residents in institutions.

### **1.4.3 Research Questions**

According to Clough and Nutbrown (2002: 36) the research question entails the following:

- Identify the limits of the study;
- Clarify the research study;
- Identify empirical issues

The researcher therefore has formulated the following questions according to the above guidelines and related objectives:

1. What are the institution's sexuality policies?
2. What are the views of the service providers with regard to the sexuality of people with disabilities?
3. How do the residents perceive themselves as sexual beings?
4. What challenges do people with disabilities face when it comes to expressing their sexuality?
5. What are the views of the service providers with regards to sex education in institutions?

## **1.5 THEORETICAL FRAMEWORK**

A theoretical framework is a helpful tool which creates a broader understanding of the data in a study Kvale (1996). The Anti-Oppressive Theory (AOP) is the conceptual framework supporting this study. Turner (2011) notes that AOP includes a variety of approaches and theories related to social work's commitment to social justice. This theoretical framework is helpful in highlighting different perspectives on how to look upon the sexuality of persons with disability since the essence of oppression is deep-rooted in segregation from desirable opportunities and experiences.

Oppression can be constructed through a variety of factors such as: social class; race; gender; ethnicity; sexual orientation; disability and other categories by which people can be defined as 'less than' (Turner, 2011). As a result, it breeds the idea of treating minority groups as objects of discrimination, exclusion and domination. It is commonly understood that people with disabilities occupy marginal positions in society (Oliver, 1996; Anderson & Kitchin, 2000) as a result they are denied sexual rights by service providers. The following are some of the core

values and principles embodied in anti-oppressive practice, according to Campbell (2003) in Turner (2011:350):

- “Shared values of equity, inclusion, empowerment, and community;
- An understanding that the thoughts, feelings and behaviours of individuals are linked to material, social, and political conditions;
- Recognition of the link between personal troubles and public issues;
- Recognition that unequal distribution of power and resources leads to personal and institutional relationships of oppression and domination;
- The importance of encouraging, supporting and “centering” the knowledge and perspectives of those who have been marginalised and incorporating these perspectives into policy and practice. This applies to persons with disabilities, as decisions are made on their behalf and often not meeting their needs;
- Conceiving of social work as a social institution with the potential to either contribute to, or to transform, the oppressive social relations that govern the lives of many people;
- Having a vision of an egalitarian future...”

These values and principles seek to challenge oppressive conditions and redress social injustice (Turner, 2011). AOP addresses the eradication of oppression at all stages, it may manifest such as personal, interpersonal, structural and cultural (Finn & Jacobson, 2008). Oppression takes place when a person acts or a policy is sanctioned unjustly contrary to an individual or group because of their connection to a specific group (Blauner, 2001). This includes depriving people from participating in all aspects of their lives or imposing belief systems to experience basic freedoms and human rights (Blauner, 2001).

Oppression according to Baines (2011) includes imposing belief systems, values, laws or ways of life on other groups through peaceful or violent means. Campbell (2003) also adds that oppression is when one social group takes advantage of another social group, either knowingly or unconsciously. It is often the result of influential people and decision makers exert commands over the weak. These oppressive practices are prevalent in residential facilities, where sexual freedoms of persons with disability are denied and forbidden (Anderson & Kitchin, 2000) hence, the choice of the AOP in this study.

Oppression gives the dominant group privileges and these privileges are then used to marginalise and disenfranchise the subordinated group (Turner, 2011). Further, the dominant social group can use force or social institutions and resources to achieve oppression (Turner,

2011). After a time, individual members of the dominant group do not need to do anything and unequal treatment becomes so much a part of the social institutions and structures, that it seems normal (Turner, 2011). Anti-Oppressive Practice is a set of politicised practices that frequently progress to investigate and address constantly shifting social conditions and challenges, which this study seeks to achieve.

Dominelli (2003) argues that the anti-oppressive theory is a form of social work practice that addresses the social divisions and structural inequalities in the society. This theory provides a framework for an appropriate and sensitive service by responding to the needs of the people regardless of their social status (Dominelli, 2003). The anti-oppressive approach in social work emerged as a result of ethnic minorities, feminists and people with disabilities challenging power structures (Sakamoto & Pitner (2005). It is viewed as an emancipatory approach as it is committed to social justice and change, emancipating "...people who have been subjugated by structural inequalities" (Dominelli, 1997: 3). In the same vein, it seeks to assist people in their desire to reverse the positions they occupy (Wilson & Bereford, 2000).

AOP requires power to enforce positive anti-oppressive policies, power is therefore the engine that drives both oppression and anti-oppression (Adams, 2003; Thompson, 2006). This study recognises people with disabilities as an oppressed group, especially in the area of expressing their sexuality, which includes sex as an act, reproduction and privacy. One of the principles of the AOP is that society operates within a social constructed hierarchy of differences where some people are valued and privileged and others are marginalised and exploited (Turner, 2011). For example, persons with disability are devalued by the society and their contribution(s) to society is not recognised, solely because of their disabilities (Shakespeare, 2000).

Therefore, AOP as applied in this study requires service providers such as caregivers, nurses, social workers and policy makers to examine their own experience and actions and critically analyse social structures of power and privileges. AOP insists that the dominant group recognise the power of its social standing and how that power results in societal privilege and benefit to the exclusion of marginalised people. It also encourages people with power not to make assumptions about group identity (Turner, 2011). For instance service providers can make assumptions that people with disabilities have the same needs instead of treating them as individuals.

The national slogan for people with disabilities, “Nothing about us without us” is used to communicate an idea that no policy should be decided by any authority or organisation without the full and direct participation of the group(s) affected by that policy. This involves national, disability based or other groups that are thought to be marginalised politically, socially or economically to be awarded equal opportunities (Integrated National Disability Strategy for South Africa, 1997). Oliver (2009) highlights that throughout history people living with disabilities have not been afforded an opportunity to make their own representations themselves, however, over the years this has changed through various interventions at international and national level that empower and recognise the rights of persons with disability.

The above saying has its origin in central European political traditions and subsequently became a perfect example for democratic norms and today the South African Disability Policy Makers has adopted the slogan. This means that state and policy makers have a key role to play as agents of transformation of society working with people with disabilities, so that policies are authored together with them. Also, decisions regarding provision of services should be determined in consultation with disabled people.

However, the area of sexuality is a contentious one as research proves that there is not an explicit sexuality policy in South Africa that allows institutionalised people with disabilities to engage in intimate relationships or express themselves sexually. People with disabilities should have the same sexual rights as able-bodied people (Shakespeare, 2000). History proves that they have been excluded from services and information connected to sexuality and they face negative attitudes and prejudices (Andersson, 2010).

Establishing and maintaining sexual and intimate relationships during an adult life is an expectation in most cultures (Wright, Wright, Perry & Foote-Ardah, 2007) and yet people with disabilities especially those with intellectual disability, are “sexually disenfranchised”, (Addlakha, 2007 in Gomez, 2012: 241). Every individual has their own needs, therefore the AOP will assist service providers to unlearn any misconceptions they had about people with disabilities’ needs and work with them as individuals. According to Thompson (1993), this anti-oppressive approach seeks to reduce and eliminate discrimination as well as the oppression of the people with disabilities living in residential facilities. The AOP empowers people with disabilities so that they can challenge structures of oppression. In other words, it invokes critical consciousness, especially to service providers in institutions to reconsider sex education

as a priority or to allow sexual relationships or expression of sexual desire not to be an abnormal act.

The anti-oppressive approach embodies the democratic value system and is concerned with reducing the effects of structural inequalities (Campbell, 2003). This approach is relevant to this study as it will determine the level of understanding of service providers (caregivers, nurses social workers or the management) providing services to people with disabilities when it comes to sexuality policies and their rights to freedom and expression. Literature which will be outlined in chapter 2 and 3 suggests that sexuality of people with disabilities in residential facilities seems to be repressed rather than expressed, which this study has considered as oppression.

The AOP will give a voice to the voiceless as people with disabilities are not in a position to express their sexuality. As a result, they remain unheard and suppressed and their inability to express themselves, is oppression. Many people with intellectual disability according to Bray (2003) do not have a viable means of communication and it is difficult to convey their needs and desires. This in the researcher's point of view, results in exclusion, alienation and stereotyping as they do not have a voice to defend or stand for themselves. Hence the study focused on hearing voices of service users in residential facilities.

## **1.6 RESEARCH DESIGN AND METHODOLOGY**

In this study, a qualitative research approach using an exploratory methodology was adopted. This research viewed the world from the eyes of people with disabilities and service providers through qualitative interviews. According to Greenstein, Roberts and Sitas (2003), thick descriptions are the chief characteristic of qualitative research, hence the researcher utilised this method to obtain rich and lengthy explanations from participants.

### **1.6.1 Sampling Technique and Population Sample**

This study has opted for the purposive and convenience sampling technique to select the sample. This entails selecting a sample from a desirable group of people and also one that is easily accessible. In light of this case, this study selected two homes as samples in Gauteng Province for the following reasons: the participants in both institutions are in close proximity

to each other; the two homes are residential care facilities for people with disabilities who have various types of disabilities. The institutions have a more controlled and monitored life which aids in gaining insight on how people with disabilities perceive their sexuality. In addition, this study sampled two more important stakeholders in the sexuality of persons with disability living in institutions, namely: the service providers and the service users. This is mainly because both of them have first-hand experiences in working with people with disabilities living in institutions, thus, their input adds value in understanding their sexuality.

### **1.6.2 Data Collection and Analysis**

Data collection was achieved via interviews in respect of service users and focus group discussions in respect of the service provider groups. Data analysis is categorised as the data that has been collected in order to draw meaningful conclusions and interpretations (Boyatzis, 1998). This study used thematic content analysis and coding, where interviews were recorded and transcribed. The data collected was then categorised into theme and subthemes.

## **1.7 DEFINITION OF KEY TERMS**

### **1.7.1 Sexuality**

The World Health Organisation (2002) defines sexuality in three facets, namely, as the quality of being sexual; engaging in sexual activity and; the decision to engage in sexuality. Sexuality is a central aspect of human life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

### **1.7.2 Disability**

The broad definition of disability, "...is the loss or elimination of opportunities to take part in the life of the community, equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, thereby causing activity limitations and participation restriction with the main stream society" (The Disability Rights Policy of the Gauteng Provincial Government, 2010:8).

### **1.7.3 Disability Discrimination**

Disability discrimination means any distinction, exclusion or restriction of persons on the basis of disability, which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise (WPRPD, 2015:4). It encompasses all forms of unfair discrimination, whether direct or indirect, including denial of reasonable accommodation, as something that people with disabilities in residential facilities may likely to experience.

### **1.7.4 Intellectual disability**

Intellectual disability is defined as a significantly reduced ability to understand new or complex information and to learn and apply new skills, in other words people with intellectual disabilities have impaired intelligence. This results in a reduced ability to manage individually or where there is impaired social functioning which begins before adulthood with lasting effect on development (WHO, 2010).

### **1.7.5 Capacity**

Capacity refers to the ability of a person to make a decision for themselves (Family Planning New South Wales Attorney Generals Department, June 2009).

### **1.7.6 Stereotypes**

A stereotype is “a fixed idea that many people have of a particular type of a person or thing, which is often not true in reality...” (Oxford Dictionary, 2006: 1449).

### **1.7.7 Service Provider**

In this study this refers to the following: a person with the capacity to provide services according to the Disability Act; professionals who have experience working with individuals with disabilities; caregivers, nurses, social workers and so on.

### **1.7.8 Residential Facility**

A Residential facility means a building or other structure used primarily for the purposes of providing accommodation and of providing a 24-hour service to persons with disabilities.

### **1.7.9 Sex Education**

Sex education is instruction on issues relating to human sexuality including emotional relations and responsibilities, human sexual anatomy, sexual activity, sexual reproduction, reproductive health, reproductive rights, safe sex, birth control and sexual abstinence (Tupper, 2013).



### **1.7.10 Sexual Expression**

Sexual expression is choosing to or choosing not to be sexually active and need not necessarily involve another person-self-pleasuring (Gomez, 2012).

### **1.7.11 Consent**

According to the New South Wales Attorney Generals Department (2009) consent relates to a person with a disability consenting to intimate relationship and it also permission or agreement given by the client to the relationship. A valid consent involves one's understanding to what they are consenting to, for example, caressing, kissing or penetration and they must also understand the sexual nature of the touching, as opposed to non-sexual touching associated with washing or receiving medical treatment. Additionally, the consent given by the person must be given freely and the person must understand and be able to exercise their right to refuse a sexual relationship (New South Wales Attorney Generals Department, 2009).

### **1.7.12 Cerebral Palsy**

Cerebral palsy is a physical disability, or mobility impairment that can either be an in-born or acquired with age and can also be the effect of a disease. This category can be classified using different dimensions such as upper limbs disability, lower limbs disability, manual dexterity and disability in co-ordination with different organs of the body (WHO, 2010).

## **1.8 ETHICAL CONSIDERATIONS**

All the participants were told everything that was involved in the research, that is, the aim and objectives of the study, potential benefits and so on. A consent letter was used to notify the participants about the research so that they could decide if they would take part or not. The home managers signed on behalf of the residents who could not write but were fully aware and understood what they were consenting to. Also, consent forms were written in a language that they understood.

In this study, participants also had a choice to participate and to drop out at any point during the research. If at some point, a participant felt that they did not want to take part, they were entitled to withdraw unconditionally. Despite being given this assurance, none of the participants withdrew during the interviews. Pseudo names were given to participants in the study; this was been done in order to ensure confidentiality as well as anonymity due to the sensitivity of the research topic.

## **1.9 LIMITATIONS OF THE STUDY**

There were specific challenges that were encountered during the data collection exercise. Even though rapport was built between the researcher and the respondents, two respondents were uncomfortable and therefore unwilling to be audio recorded. The researcher respected the respondents' wishes and took notes instead, to ensure no harm or further discomfort was caused during the in-depth interviews. However, this may have resulted in some potentially valuable information by the respondents being left out. Nonetheless, the researcher ensured that these challenges did not jeopardise or undermine the integrity and authenticity of the study by revising notes soon after the interviews were completed to prevent problems resulting from poor memory recall.

Uniformity of data collection was compromised, as one of the service providers did not participate in the focus group but was interviewed individually. The respondent's input was of great value to the research study as the person held a key position at the institution and therefore had comprehensive views or knowledge of the facility. However, to ensure validity and congruence of the finding, the researcher adhered to the exact interview guide that was used for service users.

## **1.10 OUTLINE OF THE RESEARCH**

### **Chapter 1: Introduction and orientation of the study**

The introductory chapter has offered an overview of the study discussing: the problem statement, the significance of the study, theoretical framework and definition of terms. It also covers the rationale, objectives and methodologies of the thesis. The subsequent chapters will present the study in more detail.

### **Chapter 2: Literature Review: Part 1**

This chapter aims at reviewing literature on models of disability and their emergence in South Africa. It outlines the purpose and services rendered in institutions for people with disabilities. Further, it also explores issues on privacy and sex education, as these are grey areas when it comes to sexuality of people with disabilities, especially those living in institutions.

### **Chapter 3: Literature Review: Part 2**

This chapter reviews of literature on sexuality of people with disabilities, followed by stereotypes and myths surrounding sexuality of people with disabilities. Also, literature on sexuality is explored with a view to understand relationships and intimacy of people with disabilities living in residential facilities.

### **Chapter 4: Research Methodology**

This chapter focuses on the research methodology adopted in this study in particular the research design, population, sample and sampling techniques of the research. Ethical considerations are taken into account in this chapter.

### **Chapter 5: Research Findings**

This chapter focuses on the presentation, analysis and discussion of findings in light of the current literature. It was structured into themes and subthemes that emanated from the data.

### **Chapter 6: Conclusions and recommendations**

This chapter summarises the main findings of the study and suggests a few recommendations.

## **CHAPTER 2: LITERATURE REVIEW- PART 1**

### **2.1 INTRODUCTION**

The purpose of this chapter is to provide an overview of the literature on studies in relation to the sexuality of people with disabilities living in institutions. This chapter focuses on the two main aspects first:

- a) Models of disability in South Africa in particular the former and current models used in South Africa;
- b) Residential facilities of people with disabilities with specific purpose on the purpose of the institutions and the livelihood of people with disabilities and;
- c) People with disabilities in particular the types of disabilities relevant to the subject matter.

The second part of the literature review which is discussed in the next chapter will focus on the following:

- a) Sexuality of people with disabilities which will be discussed under the sexuality flower model;
- b) Stereotypes and myths in particular sexual stereotypes and myths of people with disabilities;
- c) Relationships and intimacy in particular sexual expression as a human need;
- d) Sexual health and reproduction - this section discusses various aspects of sexuality pertaining to the subject matter such as contraception, sexual expression and marriage.

### **2.2 MODELS OF DISABILITY**

It is imperative to discuss the models of disability, as this study is also about institutions that accommodate persons with disability in Gauteng province, South Africa. It is therefore important to understand the background that underlines and informs disability as it pertains to Gauteng, South Africa. The past apartheid government of South Africa addressed disability as a social and medical concern, whereas, under democratic governance, it focused on the abilities of persons with disabilities rather than their differences (White Paper on the Rights of Persons with Disabilities, 2015). The models reveal how disability is conceptualised, how it manifested as well as how the models were used by disability movements to implement policies. There are

two main traditional models of disability that apply to the study namely: (i) the Medical model and (ii) the Social model (Oliver 2009).

### 2.2.1 The Medical Model of Disability

The first model of disability to appear was the Medical or Biological model, also known as the Individual model. The assumptions characteristic for this model focuses on the individual with the disability and in particular, on his or her biological, physical defects (Shakespeare, 2000). It has been the most influential model informing the disability policy in Britain (Andersson, 2010). The model had its focus on symptoms as disability was seen as something that can be cured by medical treatments and rehabilitating interventions. The medical model of disability generally involves organisations for people with disabilities that are usually controlled by able bodied people who provide services to persons with disability (WPRPD, 2015).

This model has its own limitations as it is focused mainly on the medical aspects and false generalisations. The model postulates that people with disabilities are unable to take part in sexual activities as the focus is on their physical impairment, neglecting other disabilities (Shakespeare, 2002). The medical model also created dependency on state assistance and has seriously reduced people with disability's capacity and confidence to interact on an equal level with other people in society. According to Chapell (2013) the model focused much on the problems people with disabilities had with their bodies and the language used to define disability. He also notes that it reinforced ideas of people with disabilities being dependent, passive and less competent to make decisions for themselves. This notion is further explored and discussed in the study, as it points out the perspectives people have towards disability and sexuality.

Johnstone (2009) rightly criticised the model as it focused on 'treating' the individual. In the same way, the treatment discourse creates negative feelings of failure and shame since not all disabilities can be treated or cured. Furthermore, Siebers (2009) discusses how people with disabilities are not expected to be able to reproduce, with the concern that they may not produce "quality off-springs", since reproduction is a matter of forwarding qualities and abilities to the next generation. He further indicates that there are certain qualities that one is expected to have if one should be able to produce children. For example, one should attract a partner, be able to

have sexual intercourse and should be fertile (Anderson, 2010). This aspect too is investigated in the study.

It is important to note that the medical model defines and labels people with disabilities as having a medical condition for example, having an intellectual disability, instead of referring to an individual by his or her name (Shakespeare, 2000). Also, the medical model meant that professionals viewed people with disabilities as sick and the only solutions necessary are medical ones (WPRPD, 2015). Thus, people with disabilities were perceived as only merely sick and not as people that needed to participate in all facets of life in the community. This is of great concern to this study as will be shown in subsequent chapters. It also meant that the voices and choices of people with disabilities were not respected and this resulted in social attitudes that isolated and condemned them to perpetual dependency (Turner, 2011). This led to oppressive practices that are understood from an anti-oppressive theoretical lens and which this study aimed to investigate.

Another limitation of the medical model is that people with disabilities seldom have any input in the aims, objectives and management of the organisations in which they reside. For this reason, the South African Disability Policy has moved from the medical to the social model which is discussed in the subsequent paragraph.

### 2.2.2 The Social Model of Disability

The social model of disability was developed by the Union of the Physically Impaired against Segregation in 1976 (Shakespeare, 2000). A 1976 publication described disability as a social oppression instead of an individual impairment, aimed at generating new perspectives on disability (Andersson, 2010). Further, Andersson (2010) indicates that ideas that disability existing at a society level instead of belonging to the individuals, had been flourishing in the disability movement for years. By the end of the 1980s these ideas were conceptualised and became the basis upon which the social model was founded. Oliver (2009) emphasised that the model must not be seen as a theory, but as a tool that can bring equal rights and freedom to various kinds of people including those with disabilities. Moreover, it is based on the concept that disability is the result of a social structure that excludes certain people from accessing employment, social resources and positive identities.

Prior to the development of the social model, research focused on addressing each individual's disability rather than the existence of influential external social barriers (Andersson, 2010). Also, people's understanding of individual sexuality broadened such that they can acknowledge that one's sexual development is a multidimensional process (Oliver, 2009). This includes the basic needs of: being liked and accepted; displaying and receiving affection; feeling valued and attractive; sharing thoughts and feelings (Oliver, 2009). This study has been motivated, in part, by this reasoning, and its findings also affirm the above (see Chapter 5). The social model of disability acknowledges capacities and abilities of persons with disabilities, thereby promoting informed decision-making and disability rights (Shakespeare, 2006; Andersson, 2010). This gives people with disability the liberty to give consent to express themselves sexually as part of their human rights. This is one of the arguments that forms the basis of this study especially in the area of policy formulation and the possible way forward.

Shakespeare (2000) asserts that the social model claims that people with disabilities are an oppressed social group. Shakespeare further argues that, the model distinguishes between impairments that people have and oppression which they experience. The social model was important in the British Disability Movement for two main reasons. First, it enabled the identification of a political strategy, namely, barrier removal. At the heart of the barrier removal was the notion that if people with disabilities are disabled by society, then the priority was to dismantle these barriers, in order to promote their inclusion. Instead of pursuing medical care or rehabilitation, it is better to pursue a strategy of social change or even total transformation of society (Barnes, 1991 cited in Shakespeare, 2000).

The following is a summary of the key features of the Social Model (WPRPD, 2015: 21-22):

- “Acknowledging that the social context within which persons with disabilities live impacts on their full participation, inclusion and acceptance into mainstream society;
- Acknowledging that disability is a social construct that results from the interaction of various actual or perceived impairments with barriers in the environment;
- Focusing on the abilities of persons with disabilities; respecting their diversity and aiming to address the social barriers that result in discrimination;
- Promoting broader systemic and attitude changes in society;
- Promoting mainstreaming of disability and;
- Reinforcing the importance of being part of transformation processes to improve the quality of persons with disabilities...”

The model emerged as a result of the desire of persons with disabilities to have more control over their lives, as well as a greater participation in civic life (WPRPD, 2015). This was an attempt to switch the focus away from the functional limitations of individuals with the intention of eradicating the problems caused by disabling environments as well as barriers and cultures (Oliver, 2009). In the same vein, Shakespeare (2006:29) succinctly describes the model as “rather than essentialising disability, it signals that the experiences of disabled people is dependent on the social context and differs in different cultures and at different times.”

Persons with disability in South Africa mobilised and organised themselves and espoused the social model, which was based on politics and apartheid (Hanass- Hancock, 2008). The model was then acknowledged by the country’s leading disability movement, Disabled People South Africa (DPSA) and has formed the theoretical background of the government’s White Paper and the Integrated National Disability Strategy for South Africa (Office on the Status of Disabled Persons, 1997 in Chappell, 2013).

In essence, the social model was criticised as its key elements define disability as a social oppression, not an impairment and also because it claims that persons with disability are an oppressed social group (Oliver, 2009) which Anti-Oppressive Theory recognises. This study agrees with Oliver that the social model seems to neglect the disability itself, that is, the impairment that one has. In as much as society’s misconceptions and barriers further disable and incapacitates people with disabilities, the social model does not acknowledge the presence of the disability. This is a concern that will be addressed in this study.

The social model was also censured for placing too much focus on the environment which can make one forget individual impairments or needs (Shakespeare, 2006). Also the social model was further condemned for being a model that considered only white middle-class men, living in towns, yet in the villages there are environments which are more disabling particularly women. It is disputed if the model had similar applicability and concerns for all races and social groups (homosexuals or bisexuals) or other impairments other than physical disabilities (Chappell, 2013). More so, it had been criticised for not including perspectives on sexuality, gender, and disability (Andersson, 2010). Despite these and many other shortfalls, the social model is still used in South Africa to redress social barriers and accessibility issues of people with disabilities.

The government, through the Department of Social Development is mainly responsible for taking care of people with disabilities, particularly those who are vulnerable that have also



dysfunctional families. In this regard, there has been growth in the development of residential facilities which house people with disabilities as discussed below. This discussion is a built-up to the comprehensive understanding of residents, their circumstances, livelihoods and challenges that are faced by people with people disabilities which is the main focus of this study.

## **2.3 RESIDENTIAL FACILITIES FOR PEOPLE WITH DISABILITIES**

### **2.3.1 Purpose and Services Rendered by Residential Care Facilities**

As discussed already, this study focuses in the main on understanding the sexuality of persons with disabilities in institutions. This section provides a brief background on the types of services that people with disabilities receive in institutions and how these services impact their lifestyle. The purpose of residential homes for people with disabilities is to provide (i) integrated and developmental programmes; (ii) services and facilities to promote their wellbeing and (iii) protection. This is primarily done by the government in conjunction with the support of other stakeholders such as the private sector, international donors and the civil society (Department of Social Development, 2010). The objective is to provide comprehensive and continuous services to persons with disabilities on a temporary or permanent basis with a view of addressing their physiological, social and emotional wellbeing.

There are four levels of rehabilitation that are used to cater for people with different kinds of disabilities these are the primary rehabilitation services, secondary level rehabilitation, tertiary level rehabilitation and specialist and academic rehabilitation (The Disability Rights Policy of Gauteng Provincial Government, 2010). This study focused on tertiary level rehabilitation which involves statutory services that include residential care facilities, foster care and adoption services (Department of Social Development, 2010). This seems to be where most people with disabilities reside.

Residential care facilities for people with disabilities have been associated with rules and regulations which are prohibitive of their sexual rights. Rosenthal and Kanter (2000) argue that, many countries in the world today deprive people with disabilities of their rights and liberties by involuntarily locking them away in institutions. The argument raised by Rosenthal and Kanter is discussed further at some point in this study.

A residential facility according to the National Department of Social Development (2010) is a temporary or permanent care, which offers protection, support, stimulation, skills development and rehabilitation of people with disabilities, who due to their disabilities and social situation need care. The Department of Social Development in South Africa is responsible for the development and administration of the legislation which guides and impacts social development services to people with disabilities such as residential facilities. The government has the responsibility to ensure that people with disabilities are in environments that maintain or improve their physical, social and psychological wellbeing, who, for a variety of reasons, are not fully able to care for themselves (The Department of Social Development, 2010). Part of this study will discuss the extent of effectiveness of this care that is provided in residential facilities.

Residential facilities offer services to people with disabilities to enhance their wellbeing. The government has established other institutions such as protective workshops, home-based care, independent living facilities and frail care centres to offer rehabilitation services to people with disabilities in South Africa (Integrated National Disability Strategy: White Paper, 1997). Rehabilitation services are rendered to people with disabilities to help them to reach and maintain their functional levels. Further, rehabilitation entails a process where people with disabilities are provided with tools to enable them to reach and maintain their best physical, sensory, intellectual, psychiatric and/or social functional levels (National Department of Social Development, 2010).

### 2.3.2 Livelihood of People with Disabilities in Residential Institutions

Every household has rules, so do residential facilities for people with disabilities. Many scholars discuss issues of lack of any privacy as it relates to sexual expression. Bernet (2010) indicated that people with disabilities have been “emancipated” from institutions. When someone or something is emancipated it means, it was suppressed or inhibited before. This statement exemplifies concerns addressed in the study about oppression of people with disabilities who reside in residential institutions.

Shakespeare (2000) notes that for many people with disabilities in segregated institutions, sex is never on the agenda. This further shows how sexuality of people with disability has always been an unpopular subject. Scholars like McVilly, Roger, Stancliff, Parmenter and Burton-

Smith (2006) point out that prohibitive environments in which service providers and/ or family members maintain the belief that people with intellectual disability are external children, restrict a person's access to social opportunities. This study resonates with this idea as service users are often viewed as children and thus that they do not need sex. The researcher does not agree with this assumption that people with disabilities do not need sex as not all disabilities deter one's need for sexual fulfilment or urge.

This research focused on whether residents, that is people with disabilities are allowed to express their sexuality, also if they are allowed to have sexual relationships with one another and if there are sex education programmes that guide them in order for them to live their lives to the fullest and enjoy their rights as they should. In this regard, the privacy of persons with disabilities needs to be protected, as in the case of able-bodied persons. The following section discusses the issue of privacy in residential facilities.

### 2.3.3 Privacy

Privacy is also an area of concern for the researcher as literature suggests, that people living in residential facilities do not have a right to privacy. Even though there is not a sexuality ethic, the sexual lives of people are private. Privacy is a fundamental right, hence it is essential for human dignity to be protected. Article 6 of the UNCRPD, asserts that persons with disability have the right to privacy. This includes the right to personal information and confidentiality of their health information. Literature suggests that despite advances to change the status quo of people with intellectual disability, there exists a lack of privacy and lack of control in the resident with the disability becoming and a captive of care (Goggin & Newell, 2005).

According to Eastgate (2002) people with disability who need physical care such as toileting, bathing may want intimacy but may not be permitted by their parents or caregivers to enjoy this right. Cole and Cole (2005) assert that, when a child develops, they demonstrate independence and curiosity about themselves. This includes their sexual bodies. The above-mentioned authors argue that a child with a disability's interpretation can be altered as they may have family members or carers who oversee and supervise the child and by so doing, interfere with their privacy. This affects perception of their bodies, its function as well as personal boundaries, regarding appropriate and inappropriate touch (Cole & Cole, 2005). This study acknowledges the difference that may exist between privacy of individuals with and

without disabilities, however, it is believed in this study that people with disabilities should be given privacy and opportunities to express their sexuality.

It appears that in principle, staff and families, especially of those with intellectual disability, recognise the rights of people with disabilities to express their sexuality; however this does not generally translate into practice (Gomez, 2012). Cuskelly and Gilmore (2007) suggest that people with intellectual disability may find sexual expression difficult to achieve because of service barriers including institutionalised living associated with lack of privacy and sexual health education. Hollomotz (2009) also echoes this idea, highlighting that people with intellectual disabilities are denied their sexual rights and rights to privacy. Lofgren-Martenson (2004) adds that people with disability often feel that their personal lives are monitored. Kempton and Kahn (1991) endorse this as they stated that it is impossible to obtain a private space for sexual intercourse for institutionalised persons with disability. In a research study conducted of young adults with Downs Syndrome, 73% of them expressed interest in the opposite sex and masturbation, however, the structure of the institution did not allow privacy required for any sexual activity or relation (Sevais, 2005).

A lack of privacy and approval was also observed by Lessliers and Van Hove (2002) in their study of 46 individuals with intellectual disability in Flanders, Belgium. When asked about sexual intercourse, many respondents openly articulated a desire for intimate relations but were hindered in this behaviour due to lack of privacy. They also indicated that their caregivers disapproved of their desires and many experienced guilt and shame about their sexual feelings. This is an indication of how people with disabilities are marginalised and denied their right to sexual expression, which the theoretical framework of this study addresses.

Bernet (2010) notes that innocent romantic behaviour like holding hands is prohibited because of such restrictions (McCarthy, 1996 cited in Hollomotz, 2009) and therefore, sexual encounters among residents (people with disabilities) in residential facilities may occur in public environments. As for privacy, 42% of staff carers in Evans, McGuire, Healy and Carley's 2009 study, stated that service users should be allowed their privacy, a quarter of that sample however did not know whether service users should be entitled to privacy in terms of having unsupervised relationships. These encounters, from the researcher's point of view oppress and repress sexuality of persons with disability and reflect a lack or no provision of sexual health education to persons with disability, which is discussed below.

#### 2.3.4 Sex Education

Sexuality encompasses a lot of aspects and sex education is one of them. People with disabilities are considered to have to have little sexual experience (Cheng & Udry, 2005) and rarely participate in sex education programs (Murphy, 2003; Murphy & Callaghan, 2004). As a result people with disabilities will have little knowledge on safe sex practices, contraception and sexually transmitted diseases (McCabe, 1999; Galea, Butter & Iacono, 2004; Murphy & O'Callaghan, 2004) and sexual consent and abuse (Thompson, 1997 & Owen Griffith, Feldman, Sales & Richards, 2000).

People with intellectual disability often largely depend on sources that may not divulge reliable information about sex (Bazzo, Nota, Soresi, Ferrarari & Minnes, 2007). This is of concern to the researcher as it implies that service users may not know appropriate ways to express their sexuality as a result of a lack or no sex education programs. Literature also suggests that they rely on family members and service providers for sex education as they spend most of their time in settings such as residential facilities, workshops, hence their sexual knowledge will be obtained through the staff at these organisations (Servais, 2006) who themselves may have biased views on sexuality.

There is a general fear that if service providers open the door for sex education to people with intellectual disability, they will be abused or become sex offenders (Hamilton, 2009). Service providers and the general public's conservative attitudes directly influence the behaviour and perceptions towards people with disabilities' sexuality (Cuskelly & Bryde, 2004). In a survey conducted by Evans, McGuire, Healy and Carley (2009) in west Ireland of community based carers for people with intellectual disability, the focus was on assessing the views of personal relationships and sexuality of service users. Results showed a significant percentage of staff who discussed sexuality with service users compared to family members. Respondents were asked about their confidence in having such discussions with service users; both staff and family carers were not confident. They expressed concern over a lack of knowledge and confidence in discussing intimate relationships of persons with disability. Vague organisational guidelines and parental wishes were identified as obstacles to sexuality and sexual health education of service users (Evans et al., 2009).

In other words, family carers did not know how to explain sexuality issues and were uncertain about how to discuss sex education matters with their family member who has a disability. The

majority of the respondents expressed support for friendships and non-intimate relationships. For those that supported intimate relationships and marriage, they highlighted that sexuality could be pursued only where there was mild or moderate disability. Only 20% of both staff and family carers received training in discussing sexuality with service users. This therefore suggests that most of the carers do not have knowledge on how to discuss sex education programs with people with disabilities, which, in the researcher's point of view is a disservice to people with disabilities.

In a study that was conducted on attitudes of Certified Rehabilitation Counsellors (CRCs) on their attitudes and comfort in addressing disability and sexuality issues by Kazukauskas and Lam across United States. A greater percentage of them indicated reluctance and discomfort when it comes to sexuality of people with disabilities (Kazukauskas & Lam, 2010). Reasons cited were mainly that they have inadequate support or no facility policy on sexuality which discourages them from addressing such issues (Davis & Schneider, 1990; Foley, Poster, Sheridan, Brown, Hatch & McDonald, 1999; Lumley & Scotti, 2001). Thus, literature proves that most staff do not have the capacity or understanding of sexual health education or how to communicate and or conduct sex education programs to service users.

Gilmore and Chambers (2010) conducted a research on attitudes towards the sexuality of individuals with intellectual disabilities. The study revealed that parents held conservative views while disability support staff was moderately liberal. Parenting by persons with intellectual disability is commonly regarded more carefully than other disabilities (Brantlinger, 1992; Cuskelly & Bryde, 2004; Wolf, 2004). There were generally liberal views when it comes to sexuality, however, factors like age and education, determined the respondents' attitudes. Older people held more conventional attitudes than young people, higher levels of education were associated with more open-minded views (Brantlinger, 1992).

Furthermore, Kazukauskas and Lam (2010) echo the notion that service providers have limited knowledge on sex education for persons with disability, as they indicate that 65% of counsellors or staff members working with people with disabilities regarded themselves as having inadequate and/ or lack of knowledge about sexuality related topics including bowel and bladder, assistive devices, fertility and so on. The service providers also expressed discomfort in addressing topics such as body image, sexual inclinations, pornography or masturbation (Booth, Kendall, Fronek, Miller & Geraghty, 2003). Chappell's research on

youths with disabilities highlights that parents of children with disabilities, their educators and health professionals showed a lack of skills in dealing with sexuality of people with disabilities.

Clearly, literature substantiates that family members and service providers of people with disabilities have limited or little knowledge on how to address sexually related issues with people with disabilities. There is a sense of fear and reservation, also, that people with disabilities may not understand sex education programs due to their disabilities. This according to the researcher, is probably due to a lack of knowledge or comprehension on the part of service providers and family members, of the kind of disabilities that the service users have, as well as a lack of training in addressing this issue. One can easily conclude that a wheelchair user has a mental disorder or intellectual disability, and therefore may never understand or learn about sexuality. There is a need to appreciate the sexual needs of persons with disability, which leads to the next discussion below, on the different types of disabilities which are associated with various misnomers.

## **2.5 TYPES OF DISABILITIES**

As has been already discussed above, the definition of disability has been subject to various socio-historical discourses, however, this research mainly focused on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006:1) which defines disability "...as an evolving concept which results from the interaction between persons with impairments and attitudinal and environmental barriers." The UNCRPD (2006) also recognises persons with disability as long-term physical, mental, intellectual or sensory impairments, which, in collaboration with other barriers, may impede their full and effective participation in society on an equal basis with others.

The term is used to refer to individual functioning including physical, sensory, cognitive and intellectual impairments and also various types of chronic diseases (WHO, 2010). The definitions of disability have evolved over time, which is a reflection of progress of society towards people with disability, as names like crippled, handicapped or disabled were used to refer to a person who has a disability (INDS, 1997).

The issue of vulnerability and being taken advantage of, are among the reasons policies regarding sexuality of people with disabilities is a concern. Scholars like Shutterworth and Mona (2002) contributed to the disability and sexuality literature which focuses on access

concerns. Since physical impairments and mobility, physical barriers and accessibility issues, for example buildings or places that do not have elevators or ramps where one has to use the stairs or escalators, there are constraints when it comes to meeting partners. Also discussed in the literature is whether a person with a disability should have an intimate relationship with a non-disabled person; as well as discussing to what extent they are considered 'equal', as society regards the person with a disability as vulnerable or a victim (Shutterworth & Mona, 2002). This, in the researcher's point of view, results in some people tending to take advantage of a weaker partner; the person with a disability can be dominated against their will.

People with disabilities are more vulnerable to sexual assault than the general public, being targeted due to the physical and/ or intellectual disability that they have. Reasons for vulnerability also include poor understanding of what is appropriate, difficulty negotiating equal relationships and difficulty reporting abuse (O'hara & Martin, 2001; Valenti-Hein, 2002). Also they may not feel they have a right to make their own decisions about sex or may be manipulated into an abusive relationship with rewards or flattery (Polusny & Follette, 1995).

Shutterworth and Mona (2002) discuss cultural prosecution and widespread discrimination and exclusion of persons with disability, particularly those with intellectual disability (who may or may not experience a sensory or physical disability) from access to sexual health education and intimacy.

### 2.5.1 Statistics and Prevalence of Disabilities in South Africa

Statistics and prevalence of disability in South Africa is relevant in this study as it will provide the reader with information on disability prevalence, with a particular focus of Gauteng, which is the area of interest in the study. There is a lack of reliable information on the nature and prevalence of disability in South Africa. This is because statistics are undependable due to different definitions of disability and different survey technologies used to collect data (The Disability Rights Policy of Gauteng Provincial Government, 2010). Also, negative traditional attitudes towards persons with disability and poor service infrastructure in underdeveloped and violence ridden areas have hindered the collection of information, affecting the overall picture (The Disability Rights Policy of Gauteng Provincial Government, 2010).

However, according to the WPRPD (2015) approximately 1 111 063 South Africans received disability grants in 2015. The KwaZulu-Natal province had the highest access to care



dependency grants 28.7%, followed by Eastern Cape 15.1% and Gauteng 12.8% (WPRPD, 2015). The province of KwaZulu-Natal also had the highest access to disability grants 25.5%, followed by the Eastern Cape Province 16.5% and the Western Cape 14%.

**Table 2.1: Statistics of people with disabilities according to racial and gender distribution in South Africa**

Race	Figure	Total	
Black African	1 854 376	Male	Female
White	191 693		
Coloured	168 678		
Indian/ Asian	41 235		
		2 255 982	

Source: STASSA, Disability Rights Policy, Gauteng: 2010: 18

Table 2.1 depicts that the highest concentration of disability exists in the Black African population group and that the male to female ratio is unremarkable.

To contextualise this review, it was necessary to discuss the type of disabilities that formed the basis of this study. The researcher focused on two types of disabilities, Cerebral Palsy and Intellectual disability, as the selected institutions from which the sample is derived, have the majority of residents with those disabilities.

### 2.5.2 Cerebral Palsy

The researcher focused on residents with Hemiplegia and Diplegia, which are types of cerebral palsy. These types of disabilities were suitable for this research as issues of mobility and accessibility are seen as barriers according to the medical model of disability. There is concern as mobility constraints can hinder them from meeting potential partners. Also according to Shakespeare (2000) there are concerns regarding intimate relationships between wheelchair users and able-bodied individuals, as it is considered taboo. The reason for exploring cerebral palsy, was also to shed light on the disability as there are myths and generalisation that all people with cerebral palsy have a mental illness or intellectual disability, which is not necessarily the case in some instances.

Cerebral palsy was discovered in the 1860's by William Little, an English surgeon. He detected the stiffness in children's arms and legs called Spastic Diplegia (Rosenbaum, Paneth, Leviton, Goldstein, Bax, Damiano, Dan & Jacobsson, 2007). Cerebral palsy is also known as encephalopathy, which is a collective name used to describe a spectrum of chronic movement disorders affecting body movements. It results from brain damage that occurs during or after birth (Panteliadis, Panteliadis & Vassilyadi, 2013). The aforementioned authors noted that cerebral palsy occurs in about 2.1 per 1,000 live births. The disability is a group of permanent movement disorders that appear in early childhood and are usually caused by damage to one or more areas of the brain (Oskoui, Coutinho, Dykeman, Jette & Pringsheim, 2013). The movement problems can vary from barely noticeable to extremely severe (Oskoui et al., 2013).

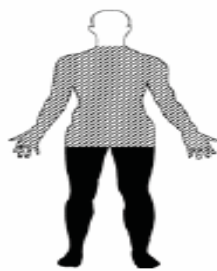
Panteliadis et al. (2013) state that the name stems from 'cerebral' referring to the brain and 'palsy' to poor muscle control or muscle weakness. The aforementioned authors assert that the muscles, nerves and spinal cord will be well functioning, nonetheless, the brain, which is responsible for relaying messages to parts of the body that synchronise movement, will be incapable to do so. Panteliadis et al. (2013) also assert that the muscles that are affected can become inflexible or extremely loose or the person may have loss of muscle control or may lose their balance and coordination. The diagram on p.30 shows the types of cerebral palsy and areas where it affects a person.

Cerebral palsy generally develops during foetal development before, during or soon after birth or during infancy (WHO, 2010). 70% of cerebral palsy cases occur in the womb, the other 30% occur due to delivery complications or post birth trauma (Yarnell, 2013). Though its symptoms may change over time, cerebral palsy is primarily not a progressive condition, as brain damage does not get worse, however, secondary conditions associated with cerebral palsy, such as muscle tightness may change as one becomes older as a result of physical stress. Cerebral palsy can be classified into several categories, it can be classified according to the body part affected, the movement disorder and the level of motor function as depicted on Figure 2.2. It can also be classified according to the severity of motor deficits as mild, moderate or severe (Jan, 2006).

**Figure 2.2: Types of Cerebral Palsy**



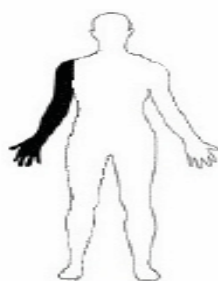
**Hemiplegia**  
One side of the body is affected. The arm is usually more involved than the leg



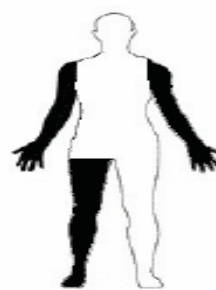
**Diplegia**  
All four limbs are affected. Both legs are more affected than the arms.



**Quadriplegia**  
All four limbs are involved.



**Monoplegia**  
Only one limb is affected, usually an arm.



**Triplegia**  
Three limbs are involved, usually both arms and a leg.

**Source: Cerebral Palsy Blog- [physio-pedia.com](http://physio-pedia.com)**

Cerebral palsy cannot be cured, but it can be maintained through physical rehabilitation (Kent & Ruth, 2013). Early signs of cerebral palsy will be noticed at the age of three. The major signs of cerebral palsy in babies are usually development delays and abnormal muscle tone. Development delay is when a child cannot stand, walk, run, sit or grab objects. Abnormal muscle tone is rigidity in the muscle or toughness in the body. Babies born prematurely usually have cerebral palsy (Nelson & Blair, 2015).

Kent and Ruth (2013) argue that many people assume that persons with disability, particularly intellectual disability are unable to learn, which is not entirely true as they are actually capable, even though it can take time. Hence, they are discriminated against due to their disabilities, which is oppressive. For example, for one to be considered to have an intellectual disability it is determined by the type of cerebral palsy one has.

Anil, Verma and Indreshwar (2012) assert that signs and symptoms differ among people, these include poor synchronisation, rigid or weak muscles or tremors, as a result it can affect one's sensation, vision, hearing, swallowing, and speaking. According to Yarnell (2013) babies with cerebral palsy have developmental delays, for example they may not be able to roll over, sit, crawl, or walk as other children their age. Also they experience difficulty with the ability to think or reason and may experience seizures which occurs in about one third of people with cerebral palsy (Kent & Ruth, 2013).

People with cerebral palsy are likely to have learning disabilities, but some may not experience any intellectual disability (Jenks, de Moor, van Lieshout, Maathuis, Keus & Gorter, 2007) hence the research has included both disabilities, cerebral palsy and intellectual disability. According to Jenks et al. (2007) cerebral palsy can be avoidable through vaccination of the mother and efforts to prevent head injuries in children. There is no cure for cerebral palsy, however, physical, speech and occupational therapy, medications and surgery may help them to get better (Yarnell, 2013).

### 2.5.3 Intellectual Disability

The earliest reference to intellectual disability may be in the Egyptian Papyrus of Thebes 1552 BC, Bryan (1930) quoted in Harris (2005). In the Roman Empire, slaves with intellectual disabilities were kept for entertainment purposes by the rich, as they thought keeping them brought good luck. However, with the emergence of Christianity in the West, perspectives shifted and a more supportive approach was expressed. The researcher notes that churches and many humanitarian organisations worldwide give charity to the poor and persons with disabilities. This is evidenced by national events in South Africa such as Casual Day, 702 Walk the Talk, International Day for people with disabilities, The Mandela Day 67 minutes, where well-wishers recognise the vulnerable in the society and wish to offer them consideration, time and money.

During the Early Middle Ages in some European countries, care for people with disabilities was primarily available for those who were wealthy; those who could not afford treatment were marginalised and excluded from societal activity (Winzer, 1993). However, this has since changed as there are residential facilities in place that offer services to people with disabilities. In South Africa, in the Gauteng province, there are about 120 registered institutions which are

funded by the Department of Social Development (The Disability Rights Policy of Gauteng Provincial Government, 2010).

Harris (2005) refers to intellectual disability as impairments in both cognitive functioning and adaptive skills whose onset is during the developmental period. It is a disorder where people have major difficulties in learning and understanding due to partial development of intelligence (Mental Illness & Intellectual Disability, 2007). According to the American Association on Intellectual and Developmental Disabilities (2001) the disability is characterised by major limitations in both rational functioning and in adaptive behaviour, which affects one's daily routines. These limitations can cause developmental delays as previously discussed.

Intellectual disability takes place before the age of eighteen (AAIDD, 2010). Their skills in areas such as cognition, language, motor and social abilities can be permanently reduced. This type of disability can be also referred to Intellectual Development Disorder (IDD) or General Learning Disability or Mental Retardation, which is a generalised neurodevelopmental disorder categorised by significantly compromised intellectual and adaptive functioning (AAIDD, 2010). The term 'mental retardation' has been changed by Rosa's Law (2009) as the term was regarded as insensitive, stigmatising, and clinically outdated. The term "retard" according to the researcher's observation is mostly used in the media (movies or comedies) when someone does something clumsy or silly, which in the researcher's point of view is demeaning and inappropriate and offensive to people with disabilities particularly those with intellectual and mental disabilities.

Intelligence tests which were developed after 1990 were used to identify children with intellectual disabilities and were placed in special classes to be better educated. Also tests were taken in order to control immigrants coming to the United States, those who failed tests were deported (Wilmschurst, 2012). It resulted to attitudes that people with intellectual disabilities are a menace and a burden to society (Galton, 1883 in Harris, 2005). Similar attitudes are also portrayed even in Africa, as discussed. These tests are also used today to test one's intelligence. The average Intelligence Quotient (IQ) of a person is 100. A person is considered to have an intellectual disability if they have an IQ of less than 70 to 75 in addition to having deficits in two or more adaptive behaviours that affect every day general living (Wilmschurst, 2012). The American Association on Intellectual and Development Disabilities (2001) states that intellectual impairment involves problems with mental abilities that affect day-to-day functioning in conceptual, which involves problems with skill in language, reading, writing

and so on. Intellectual impairment also has social effects, which refers to issues regarding empathy, judgment, communication, making and keeping friends and practical which focuses on problems with self-care, such as personal hygiene, job duties, personal finance or organisation.

**Table 2.3: The Differences between Intellectual disability and Mental Illness**

Intellectual Disability	Mental Illness
A person with intellectual disability has life-long developmental needs. Intellectual disability is a condition of slow intellectual development, where medication has no effect.	A person with mental health problems is a patient. Mental illness can be cured or stabilised with medication, psychotherapy or other support systems.
Intellectual disability can be caused by genetic factors, or by environmental factors, such as infections, or by a lack of oxygen supply of the brain during pregnancy or at birth.	Mental illness can have genetic causes, but will in most cases start as a result of coping difficulties involving feelings of depression, anxiety and confusion.
Intellectual disability is normally not caused by social or psychological causes.	Mental illness can be due to social and/or psychological causes (bereavement, loss of job, etc.).
Difficulties in learning and understanding lead to problems in school and working life and to difficulties in being included in the regular life of society. There is a large variety of appearances and degrees of intellectual disability requiring different forms of therapies or support.	Mentally illness can disturb many different functions: the senses, thinking, feeling, reasoning, violation and others. There exists a large variety of clinical pictures of mental health problems needing different forms of treatment.
Intellectual disability is permanent.	Mental illness is in many cases periodic.
People with intellectual disability need developmental therapies, education and support adjusted to their needs to be able to live included in society.	People with mental illness mostly need short-term interventions of a medical nature, but also long-term support.

**Source:** Difference between intellectual disabilities and mental illness (2014)

The rationale for inclusion of the difference between intellectual disability and mental illness is that there is confusion and misconceptions about the difference between the two disabilities (Morgan, Bourke & Jablensky, 2008). Oppression can be constructed through various factors, labelling and discrimination is one of them (Turner, 2011). A person with an intellectual disability may also have a mental illness or disorder, whereas a mental illness is a disorder that affects feelings and behaviour. The current study focused on people with mild intellectual disability.

According to experts there are three major causes of intellectual disabilities, these include; Downs Syndrome, Foetal Alcohol Spectrum Disorder (FASD) and Fragile X syndrome. The Arc of the United States (2001) categorised the causes into the following:

### **1. Genetic conditions**

These result from deformities of genetic factor inherited from parents, errors when genes combine or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and so on. Also genetic diseases associated with intellectual disability, such as PKU (phenylketonuria) which is a single gene disorder. Due to a missing or faulty enzyme, children with PKU are incapable of processing a part of a protein called phenylalanine. If it's not treated, phenylalanine builds up in the blood and causes intellectual disability. Also Down syndrome is an example of a chromosomal disorder. Fragile X syndrome is a single gene disorder located on the X chromosome and is the leading inherited cause of intellectual disability (AAIDD, 2010).

### **2. Prenatal-Problems during pregnancy**

Pregnant women who indulge in alcohol and drugs can give birth to a child with an intellectual disability. Also research has suggested that smoking also causes the risk of intellectual disability. Other risks include malnutrition, environmental toxins and infections of the mother during pregnancy such as rubella, syphilis and others (Alexander, 1998).

### **3. Perinatal-Problems at birth**

According to the American Association on Intellectual and Developmental Disabilities AAIDD (2010) prematurity, low birth weight, difficulties during birth such as temporary oxygen deprivation or birth injuries can cause a child to have an intellectual disability.

#### **4. Postnatal-Problems after birth**

Childhood diseases such as whooping cough, chicken pox, measles may lead to meningitis and encephalitis which can damage the brain and eventually causes intellectual disability. Also injuries such as a blow to the head or near drowning, as well as environmental toxins like lead, mercury can lead to brain damage and the nervous system (AAIDD, 2010).

#### **5. Poverty and cultural deprivation**

According to the Arc of the United States (2001) poverty and malnutrition, childhood diseases, exposure to environmental health hazards, inadequate health care can cause a child to have an intellectual disability.

### **2.6 CONCLUSION**

This chapter was aimed at reviewing literature on models of disability, which provided the reader with a historical background on how disability was viewed before and its emergence in South Africa. It has outlined the purpose and services rendered in institutions for people with disabilities and also explored issues of privacy and types of disabilities used in the study sample.



## **CHAPTER 3 LITERATURE REVIEW: PART 2 SEXUALITY AND DISABILITY**

### **3.1 INTRODUCTION**

The preceding chapter provided some insight on disability, through the discussion of two models of disability and a background of residential facilities for people with disability and their livelihoods. In addition, the level of privacy and sex education received in these institutions was detailed.

In this chapter, the focus will be a review of literature on sexuality of people with disabilities, followed by attitudes and beliefs about disability and sexuality as well as a focus on relationships and issues of intimacy relating to disability. Literature on sexual health and reproduction of persons with disability will also be explored.

### **3.2 SEXUALITY OF PEOPLE WITH DISABILITIES**

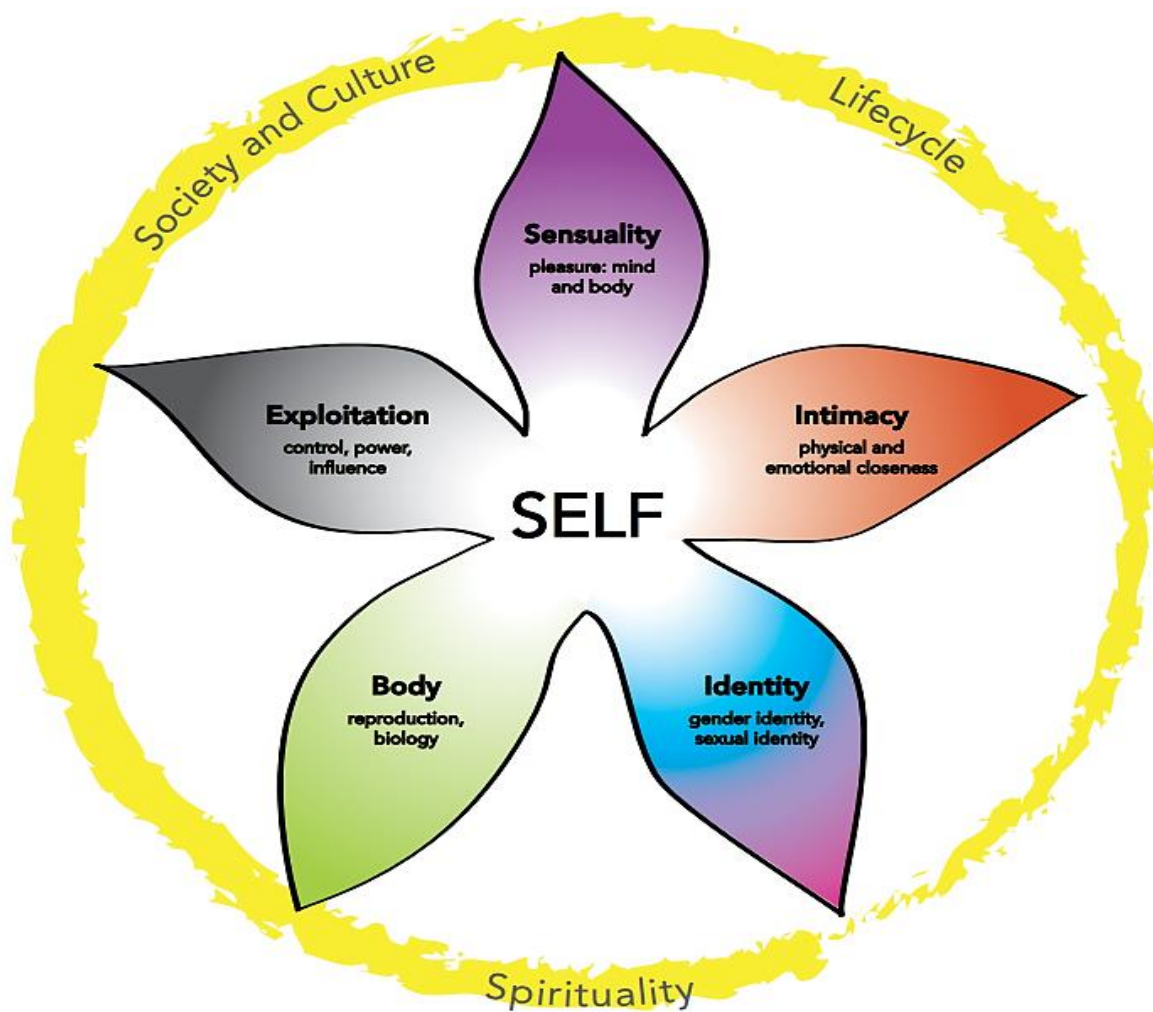
“Sexuality is an integral part of being human and can include sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction” (World Health Organisation 2002:28). Rathus, Nevid and Fichner (1997) define sexuality as the ways in which people experience and express themselves as sexual beings also being aware of their sexual role as well as in their capacity for sensual experiences and responses. It is experienced and expressed in thoughts, desires, beliefs, values, behaviours, relationships and so on. The present study explores how politics, culture and other aspects of sexuality affect persons with disability with particular attention to those living in residential facilities in South Africa.

Sexuality of people with disability can also be explained through the flower model of sexuality, which the researcher found to be useful in offering a comprehensive backdrop to the subject of sexuality. The flower encompasses three integrated models that is, a model of sexual health and sexuality, a model of self-esteem and a model of mental health (Adams, Painter & Atkin, 2014). The flower model is relevant to this study as these aspects form the nub of explorations undertaken herein. Also, the model is a tool for teaching and helps people to consider sexuality from a broader, more holistic perspective as sexuality is more than just sex. It also includes a person's sense of self, image and so on. One of the other reasons to utilise the flower model of sexuality, is because it encompasses influence of society and culture, which both contribute

significantly to how sexuality is viewed by others and by persons with disability. Further, one of the largest barriers that persons with disability face concerning their sexuality, is societal misconceptions, which will be discussed further in this chapter.

The following is the model as it may be represented diagrammatically.

**Figure 3.1: The Flower Model of Sexuality**



**Source:** Adapted from Family Planning Association of the New South Wales (2013)

The flower model is strengthened by a sex-positive approach which recognises sexual expression as a human right and a positive force in a person's life (Adams et al., 2014). This study adopted this model as it unravels the diverse components influencing sexuality as expressed across individuals, relationships, families, cultures and sexual gender identities. The model allows one to view not only the influences of society and culture as discussed earlier, but spirituality, lifestyle and upbringing. The flower model is a mechanism that assists in simplifying sexuality in order for one to understand sexuality better.

For people with disability, sexuality is often ignored, forgotten, suppressed or abused by others (predominately non-disabled people) hence, the relevance of the study is to challenge these oppressive practices and misconceptions (as per the theory frame adopted in this study). Sexuality is often thought of in narrow terms for example as synonymous with sex. For whatever reason people with disability as a group are often assumed not to be sexually active (that is, they cannot have sex, they are undesirable and their sexuality is disabled too). The researcher believes that a person's cultural and religious background can impact on the way they experience their sexuality as well as how they present themselves to the world. So culture and religion together with misconceptions around sex and disability can all negatively impact the sexual life of a person with a disability.

### 3.2.1 Petals of the Flower Model of Sexuality

As depicted in Figure 3.1, the flower has petals which represents the five areas of sexuality which are:

1. Sensuality- which is pleasure of both mind and body. This aspect is debateable for people with disabilities who may not experience these pleasures as they should, due to uncondusive environments for sexual activity.
2. Intimacy refers to relationships, physical and emotional closeness. Intimacy of people with disabilities is a concern especially for those living in residential facilities as discussed in Chapter Two. Lack of privacy and strict regulations inhibit people with disabilities from having intimate relationships, which constitute oppressive conditions that this research addresses.
3. Identity is the sexual identity, gender identity and roles. Chappell (2013) argues about people with disabilities being “de-gendered” due to the nature of care (bathing, toileting, dressing) that they go through, whereas, some of their sexual selves ache for intimacy.
4. Body is the biology of sexuality including reproduction. Reproduction of persons with disability is also discouraged, especially for people with mental illness and cognitive disabilities (Cuskelly & Bryde, 2004).
5. Exploitation refers to control, power and manipulation. People with disabilities are recognised as occupying marginal positions in society according to Anderson and Kitchin (2000) hence, freedom and right to express their sexuality is mainly monitored or

restricted, particularly those living in residential facilities. Goggin and Newell (2005) note that people with disabilities are “captive of care”. This is an indication of a lack of equality and discrimination on the part of service providers.

The flower further encompasses three holistic models that is, a model of sexual health and sexuality; a model of self-esteem and a model of mental health (Adams et al. 2004). Sexual health according to Davis (2013) is heavily intertwined with healthy self-esteem. One’s mental state affects their health and so is their sexuality.

### 3.2.2 Sections of the Flower Model of Sexuality

The flower is further broken into the following seven sections that relate to the flower model as they form part of the flower itself. These sections are related to the three holistic models as human sexuality is diverse therefore all these sections need to be explored in order to get a better understanding of sexuality as it is the focus of this study. The sections will be briefly discussed.

- Section 1 is the roots of the flower, which is basically the roots, the history or background and development of the flower. The research’s focus is on sexuality of people with disabilities, hence regarding the subject of this study, there is need to discuss sexuality origins.
- Section 2 represents the flower; they describe the common theme in the three models and how they each encompass the individual and other external factors. As previously discussed, there are various factors that affect and influence one’s behaviour.
- Section 3 is the Sexuality Flower; it describes the model and the ways in which using it will raise awareness in the field of sexual health and sexuality.
- Section 4 the Esteem Flower; just like the Sexuality flower, it deals with models to help raise sexuality awareness to gain an understanding and knowledge in sexual health issues. It also suggests a number of ways in which the petals can be reflected in working practice. One’s self-esteem is vital when it comes to healthy sexuality. Self-esteem is the fourth need in Maslow’s hierarchy of needs and according to Heydari, Mashak, and Darvishi (2009) people with physical disabilities have a lower self-esteem than people without disabilities.

- Section 5 The Mental health flower explores the relationship between mental health, sexuality and sexual health. The flower is the most recent in the bouquet of literature; it has developed and can change with time. The mental health of people with disabilities is affected by negative attitudes towards their sexuality and therefore this can affect their self-esteem, which is further discussed in Section 3.4.
- Section 6 tending your own garden; this addresses service providers responsible for the sexual health of their clients are encouraged to self-reflect first as this will boost their self-esteem and confidence that way they may impart it to their clients.
- Section 7 Resources; resources which are divided into two, namely information about resources such as books, leaflets that service providers are expected to use with their clients. The second one offers details of the relevant organisations and agencies as resources of extra information, training and support.

The following are influences on the five areas of sexuality, the relevance of these influences in this study is that, they affect one's sexuality and experiences.

### 3.2.3 Influences of the Flower Model of Sexuality

1. Society and culture- sexuality is strongly influenced by society and culture and therefore shapes a person's values, attitudes and behaviours.
2. Lifecycle- sexuality is experienced and expressed from birth to old age. A person's experience of the five areas of sexuality will vary at different life stages.
3. Spirituality- sexuality can provide people with an understanding of themselves and their place in the world. It can connect people with their sense of being human, their life force or their concept of divinity.
4. The self- as portrayed in Figure 3.1 is in the middle of the petals. According to Family Planning New South Wales (2013) it refers to the inner self, particularly one's self-esteem. A person's sense of self, wellbeing and health can be enhanced or diminished by the interplay of experiences in the five areas of sexuality and the influences from the outside. Similarly, people with disabilities who reside in facilities, are influenced by the service providers to a large extent.
5. The colours- the ends of the shapes and colours mesh together to represent their interaction and each colour has a special significance. Purple is for passion and pleasure, red is for

intimacy or romance, pink, blue or lavender represents female, male or other gender, green is for nature and biology and grey is the darker side of sexuality.

The model is one of the instruments that might be used to help remove barriers and broaden understanding so that people with disability are not further oppressed through de-sexualisation. This is the intent of the study. The centre of focus for this study is the identity petal of the flower model of Sexuality. The petal depicts how political factors and experiences of being part of a politically and socially disadvantaged group for example, living in poverty or people with disabilities can severely challenge capacity for positive sexual health (Adams et al., 2014).

To illustrate, AOP allows understanding of marginalised groups such as people with disabilities to be seen as disadvantaged and whose desire to express their sexuality is inhibited. Self-hate and externalised negative image can result in one feeling unworthy of love. This assertion, according to the researcher is reinforced by society's expectations that people with disabilities should be with people who also have disabilities or not to be romantically involved at all as they have other needs that need fulfilling before sexual ones. Again such marginalisation is appreciated from an AOP perspective and also in relation to the flower model because sexuality of persons with disability, as a form of pleasure and expression of love, is still not recognised for people with disabilities (Tepper, 2000).

Additionally, Adams et al. (2014) note that disadvantaged groups, for instance, homosexuals or people or people with disabilities, feel that their pleasure is of little concern compared with that of others; which in turn will damage positive sexuality and will result in negative sexual health outcomes. The Anti-oppressive theoretical framework used in the study concurs with afore mentioned arguments and add that people with disabilities be identified as the dominated group and their need to express their sexuality, be recognised as an area of oppression.

Harvey Milk a former San Francisco Supervisor and a politician who became the first openly gay person, quoted by Adams et al. (2014) said that if we are not free to be ourselves in that most important human of all activities, the expression of love, then life itself loses its meaning. Harvey was assassinated by a homophobic opponent for being a gay man. Similarly in this research, people with disabilities are also classified as a minority and disadvantaged group, as a result their sexuality is seen as deviant, threatening or dangerous. The sexual expression of people with disabilities is viewed as taboo in the eyes of wider society and is surrounded by silence (Adams et al., 2014). As previously discussed in the flower model of sexuality, society and culture are influences that affect one's sexuality. For this reason, the study pays attention

to the AOP as it will give a voice to people with disabilities, whose sexuality is generally oppressed and unrecognised.

The stem of the flower model of sexuality is where one belongs. This includes social networks, families and communities, for instance an independent living cottage for people with disabilities or an estate village for the elderly. One's background or kinship networks where they grow up will deeply affect the sexual selfhood and one's ability to form intimate relationships (Adams et al., 2014). Similarly, the researcher concurs with the notion that the livelihoods of people with disabilities living in institutions are rooted at the facility. Consequently, the education they receive will determine how they portray themselves, how they form relationships and also how they express their sexuality.

In a 2009 report by the Tanzania Commission for Aids (TACAIDS) persons with disability in Tanzania are reported to be engaged in sexual activities, many in high risk activities, for example, having multiple partners without using protection. This combined with the concern that women with disabilities often have a lack of knowledge on how HIV is transmitted, since they face stigma from health professionals and being seen as asexual, denies them access to health care (Kangaude, 2009). This also reflects on what society in general thinks about sexuality of people with disabilities, as it is considered inappropriate and unnecessary as if they do not need intimacy or sex education. Andersson (2010) advocates for health care for persons with disability as HIV and Aids is endemic among them.

In a survey by Wolfe (1997) in Virginia, 98 special education teachers and administrators were interviewed about attitudes towards sexuality and disability. The majority felt that sexual relations were inappropriate for people with disabilities, hence they should not have children and should be sterilised (Anderson & Kitchin, 2000). Similar attitudes are common even in South Africa. From the researcher's observation, institutions discourage sexual relations among residents with most being sterilised to prevent pregnancy. Moreover, it is believed that the contraceptive injection reduces sexual drive, which is an indication that persons with disabilities do not have liberty to express themselves sexually, even though they have rights to do so, with some guidance and education.

Shutterworth and Mona (2002) emphasise that the sexual lives of people with disabilities still remain veiled at various levels. Multidisciplinary research shows that there is much focus on gender, sexual identity, sexual orientation, and sexual behaviour and less attention has been paid to sexual access or rather sexual expression for members of people with disabilities,

particularly those who live in institutions (Eastgate, 2002). It is this gap in research and literature that the present study addresses. Efforts in the disability communities have concentrated much on universal access, equality but have excluded sexuality of persons with disability in their endeavours (Shakespeare, 2002). Equal access to sexual relationships for people with disabilities is addressed in this study, using AOP theory which addresses such injustices and marginalisation.

People with disabilities have limited access to opportunities to interact and socialise with others, or form intimate relationships (Gomez, 2012). Parents often avoid talking about sexuality with a child who has a disability because they do not believe that the child will ever have a sexual relationship (Nelson, 1995; Hallum, 1995). Likewise, opportunities to form intimate relationships are often restricted as they are regarded as children, which Brown (1994) identifies the term “innocence paradigm” because of perceptions regarding their limited intellect and understanding. For instance, individuals with intellectual or mental disabilities may have a level of functioning of an eight year old or younger depending on the severity of the disability and yet that person will be an adult; as a result they are misunderstood because the body and their reasoning do not correlate.

There seems to be a contrast when it comes to protecting the rights of people with disabilities as the rights to freedom of association and equality are being infringed and therefore their enjoyment of these freedoms and rights are extensively curtailed. Chapter 2 of the Constitution of the Republic of South Africa (Act 108 of 1996), states that equality includes full and equal enjoyment of all rights and freedoms and yet the disability rights movement has never addressed sexuality as a key political issue (Anderson & Kitchin 2000). Most researchers argue that there is much talk about rights and yet sexuality is regarded to be the area of people with disability’s great oppression (Shakespeare, 2000).

Traditionally the sexuality of people with disability has been actively disregarded and socially stigmatised. Therefore, this research study attempted to uncover the truth around the perceptions and experiences of persons with disabilities particularly those in institutions as they live in a much more controlled environment.

The following section, 3.3 discusses attitudes and belief about people with disabilities’ sexuality, which is a further focus of this study.



### **3.3 ATTITUDES AND BELIEFS ABOUT PEOPLE WITH DISABILITIES**

It is important to discuss stereotypes, misconceptions and myths surrounding people with disabilities. Over the past years there has been a growing support for individuals with disabilities to access standardised life to housing, employment, recreation and so on. However, sexuality has received less attention and support because of its multifaceted and debateable nature (Mirfin-Veitch, 2003). Goffman (2001) describes how the concept of stigma originated from the Greeks, who burned marks into bodies of persons in order to advertise their exclusion from society. The persons being stigmatised were seen to have discreditable qualities in one or several ways, referring to people with disabilities. The abovementioned author further explains that this example shows how people are divided into “the normal ones” (those without stigma) and the “un-normal ones” seen as less human (those with stigma). This segregation is a sign of oppression as discussed in Chapter 1, as per AOP, the dominant group disenfranchises the subordinate group.

Sutherland complained of stereotyping as early as 1981 and little appears to have changed since then... One of the largest barriers that people with disabilities face regarding their sexuality is societal misconceptions as discussed earlier (Neufeld, Klingbeil, Bryen, Silverman & Thomas, 2002; Mayers, Heller & Heller, 2003). Brown (2008) further argues that, there are socially accepted schemas that are embedded with a normalisation principle that people with disabilities are regarded as abnormal and unable to have normal sex.

People with disabilities are viewed as visually repulsive, helpless, pathetic, dependent, mentally retarded, endowed with mystical powers and much else (Shakespeare, 2000). Such stereotypes according to the researcher, have negative connotations which further “disable” people with disabilities. Andersson (2010) argues that people with disabilities are excluded from services and information connected to sexuality and they face negative attitudes and prejudices from society and individuals. Scholars outline that stereotypes and socio-cultural barriers are more disabling than the impairment itself (Neufeld et al., 2002). All stereotypes of disability have in common the depersonalisation of people with disabilities (Gilmore & Chambers, 2010). This exclusion and depersonalisation of persons with disabilities constitutes oppression and discrimination, areas which this study addresses by using AOP.

Below are extracts from Sutherland (1981:1, 4) showing how people with disabilities feel about labelling and stereotypes.

“One thing of which all of us are conscious is that we are seen to be different from other people, in ways that go far beyond the actual facts of our disabilities. We are subjected to a whole range of false assumptions and hostile depersonalising reactions based upon these assumptions”.

“One stereotype is that you're either in a wheelchair and helpless or on your own two feet and capable. A total change of attitude happens when you can stand up. There's a lot of stereotyping about the wheelchair; that's become a very unfortunate thing in some ways, although in a way there's a good reason for it, because the person in a wheelchair has more problems with access and things like that. Unfortunately the access sign ... shows a person in a wheelchair, has become synonymous with the word “disabled” and that connection is continually stamped into people's minds”

The above quotations highlight that society views people with disabilities as abnormal and yet, the only difference is the impairments that they have, whether physical or invisible. The researcher also notes that society has many assumptions about people with disabilities, which are not entirely true, this being the view of Shutterworth and Mona (2002) as well who lament the effect of marginalisation of persons with disability by this discrimination.

The following are some of the examples of myths concerning people with disabilities (Shutterworth & Mona, 2002; Family Planning NSW, 2013):

- All persons with disability have the same needs
- All people with disabilities do not need sex
- All people with disabilities are asexual or hyper sexual
- Adults with disabilities are not sexually attractive
- Boys and girls with disabilities do not need sexual health education
- Information and education about sex will encourage inappropriate sexual behaviour
- People with intellectual disability are incapable of understanding intimate relations
- People with physical disabilities are incapable of having sexual intercourse
- Persons with disability cannot and should not be parents
- People with disabilities should be grateful for any type of sexual relationship

- Persons with intellectual disability should not have children and should not be allowed to have children
- Adults with disabilities have more important needs than sex
- If people with disability are taught about sexuality and allowed to express their sexuality they will not be able to control themselves
- People with disability are animalistic or voracious and more likely to commit sex crimes.

These myths and stereotypes affect the livelihoods of people with disabilities and this has adversely affected their social functioning (Anderson & Kitchin, 2000). Lamb and Layzell (1994) state that there is an unspoken taboo about relationships and people with disabilities. Shakespeare (2000: 44) also notes that people with disabilities' "...sexual and emotional needs are rarely included in any discussion or representation in everyday life, whether this is in the papers and magazines we read, or the movies we watch." This is the reason the study utilised AOP theory to understand how best people with disability can be suffer less sexual disenfranchisement through various interventions which will be proposed in the final Chapter

Cultural representations of people with disabilities as sick and sexless is supported and sustained by a set of myths (Anderson & Kitchin, 2000). Chappell (2013) also highlights that the subject of sex and disability is regarded as an "African taboo". The researcher agrees with Chappell's idea, as the African culture inhibits discussions about sexuality or expression of it and anyone that is comfortable to discuss it, are viewed as misfits. Consequently, this study targeted a black African institution to establish or confirm this notion.

There are misunderstandings with regards to sexuality of persons with disability, one is that they are oversexed and yet residential facilities are known for their repressive policies and attitudes by carers. This latter aspect may suggest that persons with disabilities are asexual or that they do not need sex. This aspect is further discussed in the following section.

### 3.3.1 Asexual vs Over sexual

There is a general expectation within health services and society in general that people with disability are asexual or uninterested in and unable to perform sex and also people with intellectual disability should be denied the opportunity to have children (Anderson & Kitchin, 2000). As mentioned above, one view is that people with disabilities are either not interested

in sex or are not capable; at the other end of the spectrum they are viewed as being excessively interested in sex and out of control in their sexual behaviour.

Hyper sexuality or an excess sexual desire is particularly used to describe sexual behaviour of men with disabilities (Block, 2000; Brodwin & Fredrick, 2010; Swango-Wilson, 2008). In this regard Morris (1991:20) notes, “We are asexual, or at best sexually inadequate. That we cannot ovulate, menstruate, conceive or give birth, have orgasms, erections, ejaculations or impregnate.” Clearly, people with disabilities (particularly those with a developmental or intellectual disability) are said to be lacking a biological sex drive, unable to partake in sexual activity and that they lack the necessary social judgement to behave sexually in a socially responsible manner (DeLoach, 1994). The researcher disagrees with the idea that people with disabilities do not have a sex drive, however, agrees with Deloach, that they may behave or express their sexuality inappropriately. These issues are explored in the study.

Andersson (2010) expresses the concern that the only way people with disabilities experience sexual intimacy is through abuse, an aspect that is uncovered in the present study. There is a societal norm that people with disabilities should be with other people with disabilities (Sakellariou & Algado, 2006). Esmail, Darry, Walter and Knupp (2010) add that, if a person is in a relationship with a non-disabled partner, there is an overlapping fear of being a caregiver rather than a partner. From the researcher’s standpoint, this is an indication that people with disabilities are viewed as dependent and there is an element of fear and embarrassment associated with a partner with a disability. Contrary to public belief, the researcher and Torices-Rodarte and Patricia (2004) argue that people with disabilities have normal desires for closeness and affection as well as persistence of sexual desire.

### 3.3.2 Being Life-long Children

People with disabilities are regarded as “lifelong children” (Pendler & Hingsburger, 1991: 123) and therefore are restricted or denied the possibility of exploring and expressing their sexuality (Anderson & Kitchin, 2000). This is quite true from the researcher’s point of view as she has had the opportunity to volunteer at an institution that accommodates adults with disabilities. The caregivers at the institution would refer to residents as their children assuming a motherly role even though they were younger than most of the residents. Also the term “life-long children” in the researcher’s opinion could be because of the level of dependency and reduced

intellectual capacity. Attitudes towards sexuality vary as the level of disability is viewed as a major determinant of one's ability to engage in sexual relationships, marriage and parenthood (Christian, Stinson & Dotson, 2001).

In many cases and institutions, there is a strong drive to either ignore or forbid and/ or prevent sexual expression of any kind, mostly meant to protect residents from sexual abuse, unwanted pregnancies (Department of Social Development, 2010). But, the researcher notes that this is oppressive, as there may be persons with disability who are capable and desire intimate relationships. Also, residential facilities for persons with disability may forbid sexual expression as they fear that this promotes sexual promiscuity and inappropriate behaviour (Gomez, 2012) an aspect which is discussed further in the next section 3.3.3.

### 3.3.3 Inappropriate Sexual Behaviours

Pendler and Hingsburger (1991) outlined that people with disabilities go through a lot of unpleasant experiences. They feel lonely and isolated, have feelings of difference, low self-esteem and lack confidence, they display inappropriate behaviour for example, masturbating in public or soliciting sex inappropriately from minors or in public (Lindsay, 2002). This inappropriate sexual behaviour leads to them being vulnerable to abuse and exploitation (Sullivan, 2000). Meaney-Tavares and Gavindia-Payne (2012) explain that people with intellectual disability experience difficulty interpreting and expressing behavioural cues within social environments. These difficulties may lead to inappropriate behaviour when it comes to expressing their sexuality.

Some people with intellectual disability may have absorbed the idea that sexual expression is unacceptable (Eastgate, 2011). Some scholars like Gomez (2012) note that these inappropriate behaviours can be due to restrictions at home leading to unsafe or illegal activities such as sex in public places, parks and so on. This inappropriate behaviours can be a result of a lack of sex education for persons with disabilities and also due to their disabilities, especially among developmental and intellectual disability. They may not be able to differentiate between right and wrong or private and public behaviour.

McCabe (1999) found that masturbation was higher and exposure to sexual activity with another person was lower among those with disabilities. The study revealed further that

masturbation or self-pleasure was more common (among people with disabilities) than having a partner. This is also an indication of how limiting residential facilities and sociocultural practices are in relation to sexual expression of persons with disabilities. Ludlow (1991) notes that self-stimulation (masturbation) may be in fact the only way to survive boredom in restrictive environments. Also, people with intellectual disability or social and communication difficulties may behave in a culturally inappropriate way without realising the offense caused (British Academy of Childhood Disability, 2008). Self-pleasure is also a facet of the flower model of sexuality, however, it seems people with disabilities are generally associated with masturbation mainly in public. Again, this has resulted in a series of negative attitudes and discrimination towards them, this aspect is discussed further in the following section.

### 3.3.4 Impact of Negative Attitudes

Attitudes are a complex collection of beliefs, feelings, values and dispositions which characterise the way people think or feel about certain people or situations (Aiden & McCarthy, 2014). The abovementioned authors argue that the past two decades have witnessed major legislative changes in the UK and in South Africa, to tackle discrimination towards persons with disabilities. This is evidenced by the birth of various disability movements and forums (WPRPD, 2015). Despite these changes, negative attitudes about people with disabilities still exist (Aiden & McCarthy, 2014). Negative attitudes surrounding disability make people with disabilities feel less attractive and unable to conduct sexual intercourse in the way they are expected (Andersson, 2010). Watermeyer (2001) identified that people with disabilities go through memories or feelings of vulnerability and dependency, feeling ashamed or unlovable. The author also added that people with disabilities fear that they are somehow unacceptable to others, not being capable or adequate, that their bodies are ugly or undesirable or that they are a burden to others.

Another implication of these attitudes is that they limit people with disabilities to express themselves sexually as they feel isolated and ashamed (Bryen & Bornman, 2014). Sutherland (1981) indicates that there is a lot of stereotyping about the wheelchair because the person in a wheelchair has problems with access and mobility. These stereotypes are a reflection of society's level of understanding towards sexuality and disability hence, this research investigated the standpoint of people with disabilities themselves and their service providers.

Stereotyped views frequently act as self-fulfilling prophecies which at the end of the day, force a person with a disability into a role that can be used to justify the original treatment. Similarly, according to Bryen and Bornman (2014) eradicating violence against people with disabilities is not an easy quest especially because of myths and misconceptions around disability. In South Africa, efforts at addressing discrimination included, The White Paper on Integrated National Disability Strategy 8 and The Education White Paper 6, Special Needs Education: Building an Inclusive Education and Training System 9. However, despite such efforts, negative attitudes and disability discrimination still prevail.

Sexuality in disability is now discussed as a precursor to relationships and intimacy.

### **3.4 RELATIONSHIPS AND INTIMACY**

Sutherland (2000) argues that there are misconceptions on the needs of people with disabilities. The author highlights that people with disabilities' needs are considered to be equal or the same. However, people with or without disabilities have in actual fact the "same need" that is the need for intimacy and a sense of belonging. According to Maslow (1943) human beings have particular needs they have to satisfy at different points in their lives; if these needs are not met there is an imbalance. This imbalance can lead to inferiority complex, low self-esteem, depression, which this of concern as sexual or intimate relationships seem like an unmet need for people with disabilities in residential institutions.

As highlighted, Gomez (2012) defined sexuality as an important part of the personality of every human being, a basic need and aspect of being human and cannot be separated from other aspects of life such as physical, physiological, social, emotional, cultural and ethical dimensions. Sexuality is one of the important needs of a person that affects one's life fulfilment (WHO, 2010) hence the need to explore Maslow's hierarchy of needs.

**Figure 3.2: Abraham Maslow's Hierarchy of Needs**



**Source: Adopted from Swartz et al. (2006:175)**

There are five stages which humans need to pass throughout their lives, these are physiological, safety, belongingness and love, esteem and self-actualisation, which human beings follow throughout their livelihood (Maslow, 1943). These needs are often represented in a pyramid shape as depicted on the above diagram, with the largest and most fundamental levels of needs at the bottom and the least need at the top. The relevance of Maslow's hierarchy of needs in this research is that sexuality plays a significant role in human beings and yet people with disabilities seem to be denied this or are 'guarded' against it. The institutions' strict policies have a negative effect on individuals with disabilities in relations to Maslow's hierarchy of needs which, the theoretical framework of this study addresses.

The following needs will be explained in depth to get an understanding of the importance of the needs according to the hierarchy and how each affects the other. Much attention is afforded to needs that are more related to the study.



### **i. Physiological needs**

Physiological needs are the physical requirements for human survival. According to Maslow (1943) if these requirements are not met, the human body cannot function properly and will ultimately fail. These needs are thought to be the most important; they should be met first, these are air, water, and food are metabolic requirements for survival in all humans. While maintaining an adequate birth rate shapes the intensity of the human sexual instinct, sexual competition may also shape said instinct (Swartz et al., 2006). This further shows how human beings are biologically built with the sex instinct, which according to Freud (1905) will manifest in the early stages of one's life.

### **ii. Safety needs**

Maslow (1943) argues that when the physical needs are satisfied, the individual's safety needs take precedence. These include, personal security, financial security, health and wellbeing. He further notes that people may re-experience post-traumatic stress disorder or transgenerational trauma due to war, natural disaster, family violence, childhood abuse and so on if safety needs remain unaddressed. Safety needs also occurs when there is an economic crisis or loss of a job there will be an imbalance.

### **iii. Love and Belonging**

When the physiological and safety needs are fulfilled, the subsequent level of human needs is relational and involves feelings of belongingness (Maslow, 1943). Deficiencies within this level of Maslow's hierarchy due to neglect, shunning, banishment, can impact the individual's ability to form and maintain emotionally significant relationships in general, such as, friendship, intimacy or family. This is confirmed by the flower model of sexuality which illustrates that emotionally significant relationships affect one's sexual health. According to Maslow (1954), humans need to feel a sense of belonging and acceptance among their social groups. These groups may be co-workers, religious groups, professional organisations, sports teams, family members, intimate partners, mentors and so on. Humans need to love and be loved, both sexually and non-sexually by others. Many people become susceptible to loneliness, social anxiety and clinical depression in the absence of this love or belonging element, which is most likely to occur for institutionalised people with disabilities.

#### **iv. Esteem**

Every human being need to feel respected, this includes the need to have self-esteem and self-respect. Esteem presents the typical human desire to be accepted and appreciated by others. Low self-esteem or an inferiority complex may result from disparities and unfulfilment of this need (Maslow, 1954). McCabe and Taleporos (2003) indicated that persons with disability particularly physical disability, have a lower self-esteem concerning their sexuality. They are perceived to be sexually undesirable than non-disabled people, therefore are not in a position to attract a sexual partner (Gomez, 2012). Andersson (2010) underlines that people with physical disabilities may feel insecure due to negative attitudes towards them.

People with low self-esteem often need respect from others, they may feel the need to seek fame or glory. However, fame or glory will not help the person to build their self-esteem until they accept who they are internally. Maslow (1954) argues that psychological imbalances such as depression can hinder the person from obtaining a higher level of self-esteem or self-respect. Deprivation of these needs may lead to an inferiority complex, weakness, and helplessness. These concerns are genuine especially for a service user living in an institution. In the same vein, the flower model of sexuality postulates that one's esteem encompasses one's self image, size, shape, physical disability and it affects one's sexual health (Adams et al., 2014).

#### **v. Self-actualisation**

“What a man can be, he must be” this quotation forms the basis of the perceived need for self-actualisation (Maslow, 1954). This level of need refers to what a person's full potential is and the realisation of that potential. Maslow describes this level as the desire to accomplish everything that one can, to become the most that one can be. As previously mentioned, Maslow believed that to understand this level of need, the person must not only achieve the previous needs, but master them. The position and value of sex on the pyramid has been a source of criticism regarding Maslow's hierarchy, as sex is placed in the physiological needs category along with food and breathing. For example, sex is placed with other physiological needs which must be satisfied before a person considers higher levels of motivation. Some critics feel this placement of sex neglects the emotional, familial and evolutionary implications of sex within the community, however others point out that this is true of all of the basic needs.

As discussed above, there were no specifications on the physical or cognitive abilities of a person, meaning that every human being has feelings and sexual needs. Also, every human being has a need to belong and to have a family that loves and cares for them. People with

disabilities experience the same range of sexual needs and desires as other people (Gomez, 2012). Sexual interest of people with disabilities are not shown to differ from non-disabled people, thus indicating that these human needs are relevant irrespective of disability (Konstantareas & Lunskey, 1997). According to Murphy and Elias (2006) individual sexuality is understood to have broadened in such a way that one's sexual development is a multi-dimensional process and includes the basic needs of being liked and accepted, displaying and receiving affection. Interaction with others also plays an important role in one's wellbeing. Hence, the lack of relationships affect all facets of a person's life and people with disability are no exception (Gomez, 2012) this aspect is also reflected by the flower model of sexuality.

Sexual needs are human needs, therefore, there is need to further explore on sexual health and reproduction of people with disabilities as they also have sexual desires and needs just like their non-disabled counterparts.

### **3.5 SEXUAL HEALTH AND REPRODUCTION**

One of the petals of the flower model of sexuality, as discussed, is sexual health. Sexual health encompasses a lot of factors, which include, social relationships (families, marriages), sensuality, and intimacy and sex (Adams et al., 2014). Sexuality and reproductive issues encountered by persons with disability is likely to be different for those with disabilities (Cole & Cole, 2005) due to their disabilities. Nonetheless, the researcher believes that this does not rule out the idea that there are people with disabilities who are capable of having children and are able to handle intimate relationships. The 9<sup>th</sup> rule of the United Nations on the equalisation of opportunities for persons with disabilities, elucidates that states should promote the full participation of people with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate people with disabilities with respect to sexuality, relationships, marriage and parenthood (United Nations, 2010). This is not legally binding, but encourages governments and policy makers to work towards the equality of people with disabilities.

According to Bambara and Brantlinger (2002); Hinsburger and Tough (2002) the concept of sexual health of people with disabilities is an extremely sensitive subject. As mentioned earlier, advances have been made in employment, housing and other aspects of community integration and equality, but not regarding the sexual needs of people with disabilities.

Women with intellectual disability were regarded as feeble-minded, immoral and carriers of venereal diseases or that they will give birth to children with defects (Pfeiffer, 2007). Goddard's (1912) description of the Kallikias presented people with intellectual disability as a menace to society, criminals, drug abusers and bearers of children with intellectual disability (Harris, 2005). In a study by Abramson, Parker and Weisberg (1988) the first sterilisation laws were passed by Indiana in 1907 which was enacted by 42 other states, as a way of breeding out individuals with disabilities. Any hint of sexual expression was misinterpreted and punished (Wade, 2002). Block (2000) and Kempton and Kahn (1991) refer to people in residential facilities as having painful history of sterilisation and overall punishment as a consequence of sexual expression.

People with intellectual disability were placed in institutions and were also sterilised and it led to an increase in institutional settings and psychiatric hospitals. This was referred to as the Eugenics Movement (Harris, 2005). The movement according to Harris (2005) stems from the belief that people with intellectual disability are not able to give informed consent for sterilisation and aimed at preventing genetic transfer of retardation. There was also segregation and prohibitions on marriage and procreation by people with disabilities.

In most states sterilisation of institutional residents was utilised, as the Supreme Court had given states permission the right to sterilise people with intellectual disability, more than 47,000 people with disabilities were sterilised (Reilly, 1991). Similarly, even though the effects are subtle in modern day democratic South Africa, the researcher agrees with Reilly (1991) and Purcell (2011) that people with disabilities in institutions are still forbidden to have children or to be married, due to strict policies of residential facilities. WHO (2009) describes that women with disabilities do not have the choice to decide if they want to be in a relationship or not and whether they can give birth to children or not, also forced sterilisation and abortion is practised.

In a survey done by Anderson and Kitchin (2000) on availability and accessibility of family planning clinics in Northern Ireland. Results showed that physical access of the clinics was partial and access to information and services were extremely limited. Family planning services are usually inaccessible to most men and women with disabilities (Shakespeare, Gillespie-Sells & Davies, 1996). In other words, Shakespeare et al. (1996) maintain that people with disabilities were not expected to be using services such as consultation, treatment nor information that family planning clinics provide.

Eastgate (2002) also highlighted difficulties that people with disabilities go through to obtain condoms, contraceptives and medical testing such as HIV or STIs especially if sexual activity is hidden or unacknowledged. There are also concerns over reproduction of people with disabilities such as fear of passing their genes to their off-spring depending on the cause of the parents' disability, some may have difficulty understanding and responding to their children's needs (Eastgate, 2002). People with disabilities are denied sexual and reproductive freedom and the liberty to establish families in forms that they choose (Butler, 1999). Additionally, people with intellectual disability have been viewed as asexual and purposefully misinformed about sexual health for instance, being told that sex is dangerous or harmful (Hinsburger & Tough, 2002).

Wolfe (1997) concurs and adds that sexuality of institutionalised people with disabilities is repressed and overt sexual expressions are punished. Hence, this research study investigated whether this was also applicable to institutions in South Africa.

Attitudes towards people with disabilities have historically been negative (Lessliers & Van Hove, 2002) but have improved over the years except in terms of marriage and procreation (Cuskelly & Bryde, 2004). This is quite true from the researcher's standpoint as most people with disabilities are allowed to have friends of the opposite sex or have relationships but, the issue of reproduction is remains unpopular. Contrary to suggestions made by Siebelink, de Jong, Taal and Roelvink (2006); Hellemans, Colson, Verbraeken, Vermeiren and Deboutte (2007) and McCabe (1999), most people with disabilities have aspirations to have children and/or intimate relationships. As alluded in the following quotation "We may well be more concerned with being loved and finding sexual fulfilment than getting on a bus!" (Waxman & Finger, 1991:1). This is a clear statement that proves that not all people with disabilities are asexual. It also demonstrates that equality rights such as universal access like wheelchair user friendly transport is not enough when it comes to addressing the rights and needs of persons with disability. Chappell (2013) also noted that current African disability studies focus mainly on rights and inclusive development leaving sexuality unaddressed. Hence, this study aimed to eradicate oppression of sexuality people with disabilities who live in institutions.

### **3.6 CONCLUSION**

Attitudes towards people with disabilities are primarily negative and their sexuality is the elephant in the room. This chapter explored the flower model of sexuality which shows the holistic models of sexuality that encompass the existence of humanity and sexuality. Also, focus was on attitudes and beliefs about sexuality of persons with disabilities. Relationships and intimacy were also discussed as linked issues. Moreover, the chapter discussed the negative attitudes and misconceptions on the sexuality of people with disabilities. Lastly, sexual health and reproduction were discussed, with focus on residential facilities' restrictive policies inhibiting sexual expression. Clearly, the sexuality of people with disability is still in the main, brushed under the carpet.

## **CHAPTER 4: RESEARCH METHODOLOGY**

### **4.1 INTRODUCTION**

This chapter outlines the rationale for selecting qualitative research method and explores the research questions that informed the methodological choices made during the study. It also outlines what transpired in the course of pursuing the research study. In addition, the relationship between the researcher and the participants, ethical considerations, data analysis methods and the limitations of the research are discussed in more detail as these were only briefly highlighted in Chapter 1.

### **4.2 RESEARCH APPROACH AND DESIGN**

A qualitative research approach was adopted for this study. According to Greenstein, Roberts and Sitas (2003: 49), qualitative research is rooted in the need to understand human-social interactions from the perspective of the insider and participants. More so, Greenstein et.al (2003) discuss the features of qualitative research which are thick descriptions and insider perspectives, which the researcher wanted to obtain in detail. This method was appropriate and suitable for this research, since the researcher wanted an in-depth understanding of the participants' perceptions and experiences, which pertain to the sexuality of persons with disabilities.

A qualitative research paradigm allows the researcher to interpret phenomena in terms of the meanings people bring. Likewise, it promotes trust and empathy between the researcher and participants (Collins, 2007). Due to the sensitive nature of the topic of this study, this approach was suitable as there were discussions on intimate details of the participants' sexuality. The main aim of most qualitative studies is to explain the various ways through which people come to understand and account for issues, events and behaviours in their lives (Swartz, Cheryl de la Rey, Duncan, Townsend & O'Neill, 2006). Therefore, the researcher attempted to gain a holistic view of the issue being studied and of the participants' perceptions, meanings and interpretations as related to sexuality.

Creswell (2003:22) defines it as an approach that is used when "...the inquirer often makes knowledge claims, based primarily on constructivist perspectives for instance interviews". This

method was relevant to the researcher as it sought to explore phenomena. It brought out the perceptions of the participants as the instruments used were flexible and allowed for constructionist interpretation of data. This meant that it helped the researcher to investigate and explain the participants' experiences and opinions comprehensively.

Using a qualitative framework, the study was exploratory and used a descriptive design. Kreuger and Neuman (2006: 96) argue that a descriptive research design "...presents a picture of the specific details of a situation, social setting or relationship and focuses on how and why questions". A descriptive study according to Rubin and Barbie (2005:15) "is more likely to refer to a more intensive examination of phenomena and their deeper meanings..." With the insider perspective, the research views the world from the eyes of people with disabilities and service providers, who are under study. Also the thick description prompted meant that the researcher got rich and lengthy explanations that participants shared and that are offered as quotations to substantiate the discussion on findings.

The research was also exploratory in nature as sexuality of persons with disability in South Africa is an underexplored subject. According to Babbie (2012) this type of research is conducted for a problem that has not been clearly studied yet but helps to have a better understanding of the problem. In this case sexuality of people with disabilities has been identified as a problem.

#### **4.3 SAMPLING PROCEDURE**

The researcher used the purposive sampling technique to select the sample as it "...selects a desirable group of people" (McBurney & White, 2009: 258). The researcher chose this sampling technique as suitable because of convenience and purpose that satisfied the research objectives. According to Davies (2007) purposive samples are non-probability samples because there is no guarantee that results obtained are correlated in terms of probability levels to the sample from which they were drawn. In this research, it is not certain that the information the participants provided applies to all persons with disability.

The power of purposive sampling lies in selecting information-rich cases for in-depth analysis related to the central issues being studied. Purposive sampling technique is often used when the researcher uses their own judgement to select those who have the required attributes for the research. The sample was drawn from two residential facilities for people with disabilities in



Gauteng. The researcher obtained information about the organisations through the Gauteng Provincial Disability Forum meetings, where organisations meet to network and share information on how to provide and improve service delivery to persons with disabilities. As the researcher is a qualified social worker, she obtained information about the homes through interaction with other service providers during these meetings.

The two selected institutions possess attributes that the researcher was interested in, as they mainly cater for adults with cerebral palsy and intellectual disability. The residential institutions have certain criteria when admitting residents; they use a tool called the Developmental Quality Assurance (DQA 98) to assess the level of frailty for applicants in a residential facility (Department of Social Development, 2010). For example, the resident must have a certain type of disability to meet the requirements of the Home in order for them to get appropriate care and intervention. The sample selected had to be a resident at the facility to qualify in the study. The researcher acquired the information from the home management, who assisted her to determine the selected sample for this study. The staff was then required to select residents (persons with disabilities) who were capable of participating in the study as the researcher was warned of possible withdrawals from certain residents who had unpredictable tendencies.

Creswell (2003) highlights that purposive sampling refers to selection of sites or participants that helped the researcher understand the problem and the research question. Furthermore, they must be willing to reflect on and share this knowledge. Purposive sampling targets a particular group of people. Therefore, the researcher purposefully selected the research participants and key informants who gave relevant and detailed information that answered the outlined research questions. A population in research is any set of people from which a sample is selected and to which the study's results will generalise (Bowling, 2009). In this study, the researcher used two samples from the selected institutions. Purposive sampling proved to be useful in selecting the samples for the study.

Four service users who were competent in verbal communication were selected from each home. The other sample was of eight service users that is residents with either physical or intellectual disabilities or both from the two institutions. The participants were between the ages of 20 and 55 years. The minimum age of the participants was selected under the assumption that most of them may have experiences relating to their sexuality. Furthermore, the researcher chose two target groups from two different residential facilities to get a

comprehensive overview to ensure authenticity of the study because they are the ones who are in a better position to tell their stories.

Correspondingly, two racial groups were chosen in order to provide some variety of ideas as cultures and experiences may differ across cultures. However, this study is not a comparative study. Helmius (2000) emphasises the importance of viewing sexuality in its cultural context. Different cultures vary in how they understand sexuality and in what they deem to be acceptable or normal. Sexuality is influenced by a number of factors such as, interaction of biological, psychological, economic, political, cultural, religious factors and so on (WHO, 2002).

The researcher therefore, chose two residential facilities which accommodate different races, as cultural factors are important in terms of sexual norms (Healy, McGuire, Evans & Carley, 2009). Furthermore, views on sexuality differ immensely between cultures and religions (Albanesse & Hopper, 2007). Human beings are born with abilities to experience sexual feelings. How sexuality is expressed is decided by cultural values of a society (Andersson, 2010).

In summary, the two samples can be described as follows:

#### 4.3.1 First Sample: Persons with disabilities

The criteria for participating in the study were participants who had Cerebral palsy specifically, Hemiplegia and Diplegia as they are likely to use wheelchairs. Mobility issues are considered as hindrances for people with disabilities, in terms of accessibility which was a barrier (Shutterwoth & Mona, 2002) that needed investigation. The chosen disabilities are of interest because those with cerebral palsy (particularly wheelchair users), are likely to face challenges when it comes to mobility. This can affect their chances of meeting people; also stereotypes on whether they can engage in sexual activities due to their physical appearances was an important consideration. Hence, the researcher wanted to gain insight related to the challenges they might face in this regard and overall, to gain more understanding of their sexuality.

In addition, the researcher chose persons with intellectual disability because they are subjected to stereotypes regarding their ability to give consent and express their sexuality, as discussed in Chapter Three. Intellectual disability was of interest to the researcher because of the

stereotypes and myths surrounding the disability which this study sought to demystify. With regard to their severity of intellectual impairment, the researcher chose participants who are partially impaired or have moderate intellectual disabilities and are able to give consent. Consent was an important ethical consideration in the study.

Additionally, the reason for choosing two types of disabilities was to get a detailed perspective from both groups as they may have different interpretations and may face different challenges when it comes to sexuality. Moreover, the reason for interviewing participants in institutions rather than from random households was that, those in residential facilities are most likely to live a more controlled or monitored life (Bernet, 2010) which aided the researcher to gain insight on how people with disabilities in institutions perceive their sexuality.

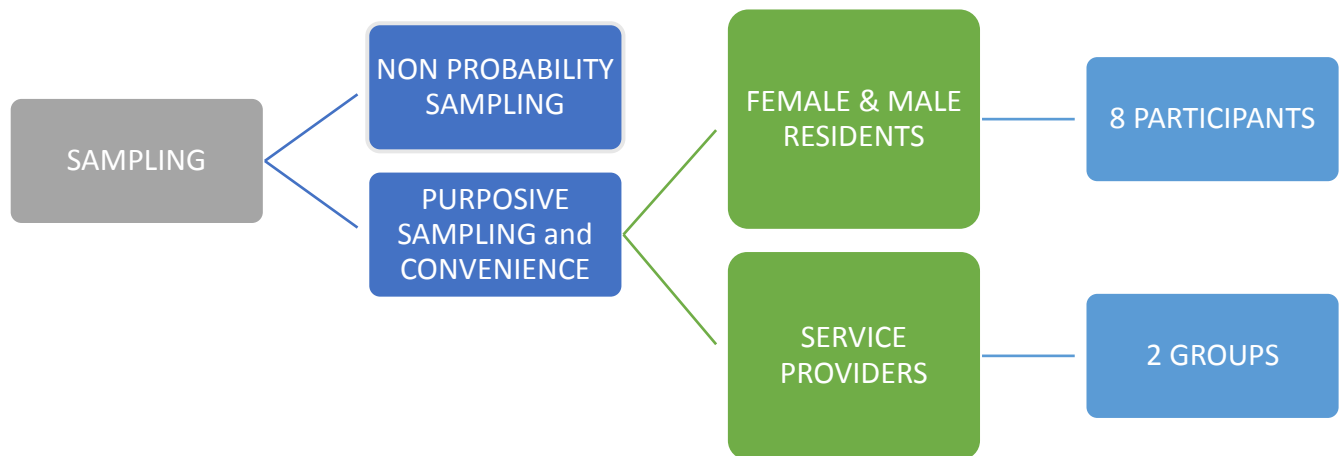
#### 4.3.2 Second Sample: Service Providers

The researcher also used the service providers from the same institutions as the first sample, as her second sample of the study- because they have firsthand experiences with people with disabilities. The home managers assisted the researcher with recruiting service providers to participate in the focus group; both groups were hence purposefully selected. Staff members had to be working at the residential facility for more than nine months to participate in the study in order that they could provide detailed information on the topic of study.

This guaranteed a better understanding on the basis of the longer they have been at the institution the more they knew about the residents (people with disabilities). Their attitudes towards people with disabilities directly affects their residents as they are the primary providers of any kind of information and knowledge the residents get on sexuality. Also, these service providers are responsible for the wellbeing of their residents hence they will be in a position to know the needs of their residents, sexuality being one of them, as well as their standpoint with regards to the provision of sexuality education and protection from sexual violence and abuse. The samples using the afore-mentioned criteria were finally derived after consulting with managers at the residential care facilities as to perceived level of cooperation and ability to participate in the study.

The sampling procedure can be summarised in Figure 4.1

**Figure 4.1: Summary of Sampling and Sampling Method**



#### 4.3.3 Triangulation

Triangulation is a method used by researchers in a qualitative study in order to establish validity in their studies. Triangulation can use more than one approach to the investigation of a research question in order to improve confidence in the subsequent findings (Guion, 2002). According to Denzin and Lincoln (1998) as cited by Bryman (2012) there are four forms of triangulation, which are data triangulation, investigator, theoretical and methodological triangulation. This study focused on data triangulation, which entails gathering data through several sampling strategies, so that pieces are gathered (Bryman, 2012). Hence in this study, data from two sample sources namely service providers and service users from two different residential care facilities were used to achieve triangulation. A key strategy is to categorise each group that the researcher is evaluating.

## **4.4 DATA COLLECTION METHODS**

According to Pope and Mays (2000) there are three commonly used qualitative methods, namely, Participant observation, In-depth interviews, and Focus groups. The researcher conducted the research by using In-Depth Interviews and Focus Groups, which will be discussed separately below.

In order to aid the flow and direction of the data collection process, the researcher used two different interview guides with pre-outlined questions. The first section of the interview questions was with willing and competent residents with cerebral palsy or intellectual disability or both, using in-depth interviews. The questions were in the form of open-ended questions in order to allow detailed opinions and perceptions of the participants. The researcher used the semi-structured interview questions as a method of information collection, to gain a detailed picture of the participant's beliefs and perceptions of sexuality of people with disabilities.

### **4.4.1 In-depth interviews**

According to Greeff (2005), in-depth interviews are optimal for collecting data on individuals' personal histories, perspectives and experiences, particularly when sensitive topics are explored. They also allow one to clarify and follow-up questions, which was relevant to the study in the case of participants with disabilities, as they were sometimes cryptic in their responses or may not have understood the questions fully. Through in-depth interviews the researcher was able to investigate how the participants interpreted their personal experiences and perceptions.

The one-on-one interviews offered the researcher room to probe deeply into the participants' social and personal issues, consequently exploring their experiences at great length. Bernard (1994:24) elucidates that face-to-face interviews offer the possibility of modifying one's line of inquiry, following up on interesting responses and investigating underlying motives in ways that postal and other self-administered questionnaires cannot. The research questions for persons with disabilities were simplified and individualised in order to accommodate those with intellectual disabilities as their competency levels are not expected to be uniform. The interview schedules are attached as an appendix at the end of this document.

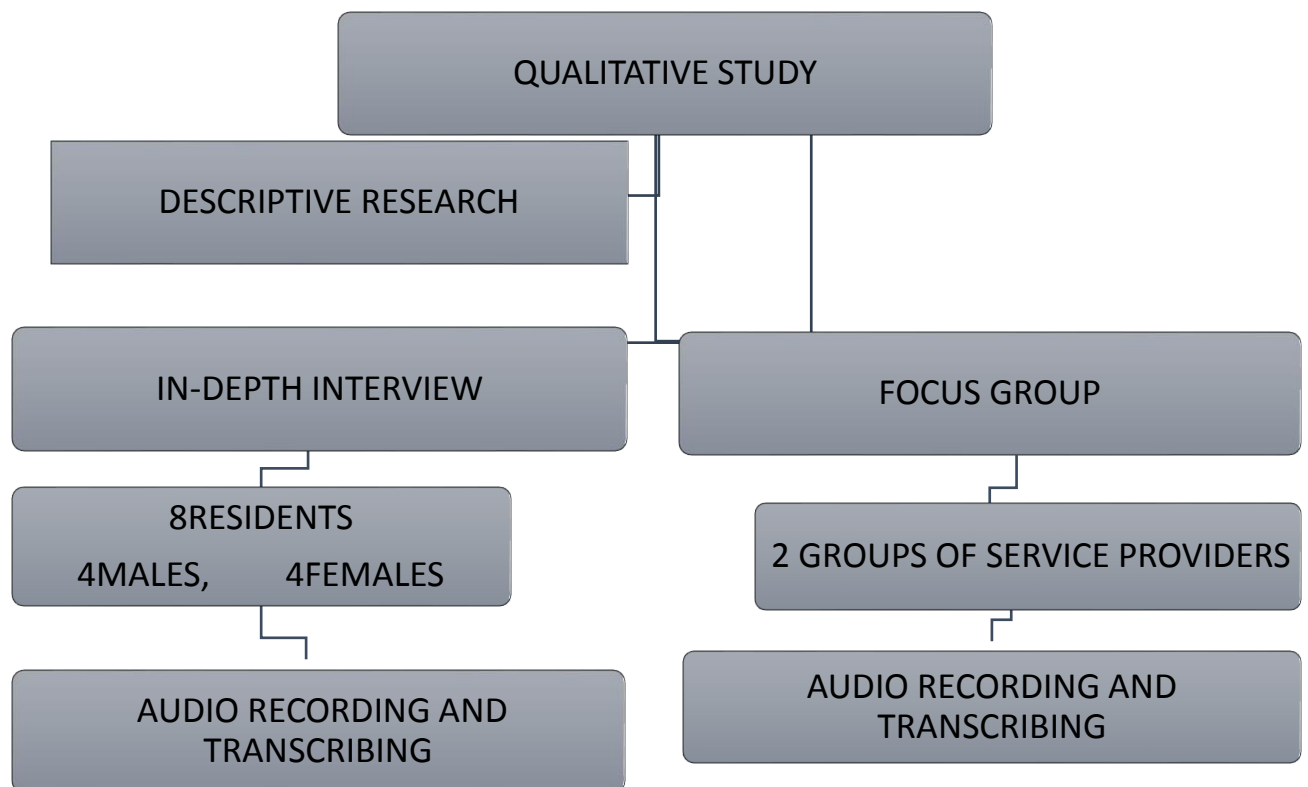
#### 4.4.2 Focus groups

Focus groups are operative in prompting data on cultural standards of a group and in producing comprehensive ideas on issues of concern to the groups epitomised (Pope & Mays, 2000) and are deemed relevant for the service providers. The other sample for data collection was for service providers (caregivers or nurses, home managers, social workers) at the Homes, which was administered through focus groups. The researcher was aware of the limitations when it comes to confidentiality in a group setting. Hence, the researcher explained to the service providers prior to the session, the essence of confidentiality as it is of utmost importance to them as an institution as well as their residents. The focus groups were ideal as they allowed interactions between the facilitator allowed room for probing issues in-depth. It also allowed the researcher to ask participants to elaborate on their responses and it generated rich discussions, thereby providing the researcher with in-depth information.

#### 4.4.3 Interpreter

The interviews and focus groups were conducted in English and isiZulu to accommodate all participants as both institutions have different race groups, specifically black Africans and white. The researcher had contact with an isiZulu English translator, who the researcher knew from the organisation she volunteered at. The interviewer chose an interpreter as Zulu is not her first language, so as to accommodate Zulu speaking participants. Preparations for the interviews were done while visualising the interview situation together in order to get a picture of how it would be to conduct the interviews working closely together. A translation of the interview questions to isiZulu was done in order to ensure that the English concepts were corresponding with those used in isiZulu. The interview schedules were thoroughly discussed to ensure that all questions do not lose their original meaning. The isiZulu interpreter assisted with interviews for both institutions, as the white dominated institution had black staff personnel. Any compromise that use of the interpreter resulted in, will be discussed under trustworthiness issues.

**Figure 4.2: Summary of Data Collection Methods**



#### **4.5 DATA ANALYSIS**

Data analysis categorises collected data in order to draw meaningful conclusions and interpretations. In this research, the researcher used thematic content analysis and coding “...whereby the data are broken down into their component parts and these parts are given labels” (Bryman, 2012: 13). Thematic analysis is a method used in the study to identify and analyse themes within data. The researcher familiarised herself with the transcripts and went through the entire data set repeatedly searching for meaning and patterns. After familiarisation with the data, the researcher proceeded to generate codes. Thematic analysis allows flexibility, provides a rich account of phenomena (Braun & Clarke, 2006) and is of particular use within early stages of research (Boyatzis, 1998). Interviews were transcribed and initial codes were noted. The data was thematically analysed in such a way that their inherent contextual character remains undistorted. Codes identify a feature of the data that can be assessed in a meaningful way regarding the phenomenon (Boyatzis, 1998: 63).

Statements with similar meaning were coded in the same way. After coding, the researcher proceeded to search for themes. Statements with similar codes were put together. The next step was to consider the meaning of each theme and how it fitted in relation to others and the overall story which is the research question were addressed. After this, specific themes were formulated from overall themes chosen from the participants' responses. This was discussed alongside the literature and the theoretical framework used in the study, which helped in contextualising quotes included under the different themes. When this was done, the researcher proceeded to write a report about the findings in relation to the research objectives.

#### **4.6 PILOT STUDY**

To check the reliability and validity of the research instrument, a pilot test using the in-depth interview schedule was conducted, was conducted. Two participants who met the same sampling criteria as those used in the main study were interviewed but were not included in the research findings. The pilot test was done to ensure validity and reliability by determining the applicability of the research questions, which speak to their relevance and whether or not they are understandable (Greenstein, Roberts & Sitas, 2003).

The pilot study was conducted for two major reasons. Firstly, the researcher wanted to test the interview schedule, to ensure that questions were clearly articulated to allow for in-depth and relevant answers. Secondly, the pilot study provided an opportunity for the researcher to familiarise herself with the research questions and to learn respondents' reactions to prepare herself for the actual study as the questions were "personal" in nature. In addition, it allowed the researcher to discover areas of the interview guide where the researcher needed to be more sympathetic or sensitive as some of the questions could potentially trigger unpleasant emotions.

The pilot test assisted the researcher to identify flaws in the interview schedules such as questions that were difficult to answer or comprehend. The questions were reviewed before conducting the actual study. It was during these interviews that it became apparent that some research questions were effective, and elicited in-depth responses. The pre-test also helped the researcher to get an idea of the average time the interviews would take during the actual data collection. De Vos et al. (2002) stipulate that a pre-test is imperative as it picks up the possible flaws and therefore helping to make necessary adjustments before carrying out the actual research. From the pilot study, the researcher knew how long each interview might take and



therefore made necessary modifications to her appointments timetable and dates accordingly. These adjustments helped the researcher to obtain extensive information.

#### **4.7 RELIABILITY, VALIDITY AND TRUSTWORTHINESS OF THE STUDY**

The key principle of a good qualitative research is found in the notion of trustworthiness, neutrality of its findings and decisions. Trustworthiness according to Babbie and Mouton (2001:34) is a concept that is concerned with the ability of the researcher to persuade the readers that his or her research is worth considering. Lincoln and Guba (1985) postulate that trustworthiness of a research study is important to evaluating its worth. Trustworthiness in relation to qualitative research involves establishing the dimensions of credibility, transferability, confirmability, and dependability. These are discussed below.

##### **4.7.1 Credibility**

According to Babbie and Mouton (2001:13) credibility is the “compatibility between the constructed realities that exist in the minds of the respondents and those that are attributed to them”. To ensure credibility of this study the researcher visited the organisations before data collection for ease of access and resultant smoothness in authentic data collection. The researcher visited both homes twice before the actual interviews; she thus had prolonged interactions with the participants in order to get acquainted with them and vice versa. The prolonged engagement allowed the researcher to elicit genuine data. It also helped to establish a relationship of trust between both parties.

In order to acquire credibility, the researcher had to use triangulation. Triangulation is the best method to get several constructions of the reality that exists within the context of a study in order to collect information about different events and relationships, from diverse sources using various methods (Babbie & Mouton, 2001). Therefore, in this study, the researcher triangulated her research through asking different questions from different sources through interviewing people with disabilities in institutions and their service providers (caregivers, nurses, social workers and the management) to ensure credibility. The participants were encouraged to be honest from the outset of each session and that they have a right to withdraw at any point of the study. This was done to ensure that participants can contribute ideas and talk of their

experiences without fear of losing credibility in the eyes of the service providers of the organisation or the researcher herself.

#### 4.7.2 Reliability

Reliability is the consistency and dependability of data so that at another time or another researcher can replicate the study and obtain dependable results. The more reliable our instruments, the more consistent and dependable our results (Vos, Strydom, Fouche' & Delport 2005). Seale (1999) argues that the trustworthiness of a research study is at the core of matters commonly discussed as validity and reliability. The researcher sought opinions from other researchers who had prior knowledge on the particular research on sexuality of persons with disability to refine the topic and to refine data instruments adequately. To ensure reliability of the research, the researcher requested the home managers and the social workers to provide information from the residents' files with a doctor's letter or medical report, which stated the resident's disability. This was done to ensure that the appropriate disabilities the researcher intended to use were considered, as there are different levels of severities of the disabilities.

#### 4.7.3 Transferability

It refers to the degree to which the findings can be applied in other contexts or other respondents (Babbie & Mouton, 2008). It involves thick description of how the researcher gathered their information so that other researchers can also replicate the study. By describing a phenomenon in sufficient detail, one can begin to evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people. It also refers to the detailed account of field experiences in which the researcher makes explicit the patterns of cultural and social relationships and puts them in context (Holloway, 1997). The researcher provided a thick description of how she collected her data as well as the time frames used in the study. The context of the research findings were clearly stipulated with sufficient detail and precision to allow judgements about transferability to be made by other researchers. Also, to ensure that transferability is obtained, the researcher purposively selected her sample and location, in this case she chose two residential institutions in Gauteng, which cater for people with disabilities.

Service providers were selected as participants of the study in order to acquire desired results and to get different opinions as experiences differ from one person to the other.

#### 4.7.4 Confirmability

This refers to the level in which the findings are the product of the focus of the inquiry and not of the biases of the researcher (Babbie & Mouton, 2008). Confirmability according to Kasiram (2015) is the degree to which research findings are determined by the participants and the conditions of the research and not the biases, motivations, interests, or perspectives of the researcher. To strengthen confirmability, the researcher made reference to literature and findings, both old and current to confirm the researcher's interpretations of the study in addition to information and interpretations by people other than the researcher from within the research study itself. To ensure that confirmability was achieved, the researcher had also used triangulation to enhance confidence in the ensuing findings by interviewing people with disabilities as well as service providers in institutions. The researcher explained how she established her findings and her research was examined by a body of professionals from the University of KwaZulu-Natal.

### **4.8 ETHICAL CONSIDERATIONS**

Ethical considerations are bench marks that guide research to promote uniformity and also to protect and not exploit respondents. According to Founche' and Delport (2003) ethics refer to a set of widely accepted moral principles that offer rules and behavioural expectations of the right conduct towards experimental subjects and respondents and other researchers. Due to the sensitivity of the subject of the study and the fact that the participants themselves (people with disabilities) are a vulnerable group, the researcher used a written informed consent which was used to notify the participants about the research. This meant that that only literate participants were used so that participants are fully appraised of issues of consent. The consent forms were written in isiZulu and English and the researcher made sure that the language was understood by the participants to ensure that they participated willfully. The consent was signed by the institution's management and residents where possible, and some gave verbal consent as they were unable to write due to their disabilities.

Also the researcher consulted each participant prior to the conduct of the interviews to establish their needs in terms of resources depending on their needs or type of disability. This was because some may have required the bathroom after a particular interval of time or some may have needed their caregiver on site for safety. All these requirements were taken into consideration to ensure that participants were safe and were fit to participate in the interviews. Nevertheless, the researcher did not encounter any such problems during the interviews.

The researcher reassured the participants of confidentiality and privacy by using pseudo identities. Also participants were provided with the researcher's name and contact information of an appropriate person to contact with questions about one's rights as a research participant; this was also done to ensure that they had contact information if there may have been any inquiries about the research. The participants were told the purpose of the research, what was expected of a research participant, the amount of time likely to be required for participation, expected risks, psychological and social benefits.

In this research, the following ethical issues were considered and are summarised below:

- Voluntary participation by respondents: This ethical consideration postulates that all respondents must be at liberty to participate in the research and should withdraw at any point when they want to discontinue with the research with no negative repercussions.
- The right of participants to informed consent: All participants have the right to be informed about the logistics of the research in order to make informed decisions (Babbie, 2012). All the participants were informed of all the processes that was going to transpire during the interview sessions.
- Right to privacy and confidentiality: Babbie (2011) believes that all the information reported by the respondents must be confidential and used only for academic purposes. This study therefore, adhered to these ethics. The participants were aware that they were being recorded and were aware of all the devices that were used during the interviews, as it was discussed with them and appeared in the letter of consent. Pseudo names were used to protect the identity of the participants and the image of their institutions. Furthermore, the names of the residential facilities and their geographical locations were not disclosed due to the sensitivity of the study topic.

As a qualified social worker, the researcher applied principles of group work practice such as confidentiality and self-determination whereby the group's purpose superseded

that of the group worker. She informed the participants, in this case, service providers, about the disclosure of confidential information and the potential consequences before the disclosure is made. The researcher also highlighted the limitations of possible breaches of confidentiality as other participants may disclose some information, however, this was addressed and made clear to the participants, that confidentiality is of utmost importance and it is for the benefit of their residents as well as themselves.

- Respect: all the participants were treated with respect and their dignity and human rights were observed (Neuman, 2007).
- Avoidance of harm: According to Creswell (2003) participants should not be exposed to any harm be it physical, emotional or even psychological harm. The researcher strived to ensure that no harm was caused to the participants during the study by checking time and again if the interviewees were comfortable. The researcher was prepared to pick up possible signs of distress or discomfort for immediate intervention or debriefing and had alerted key personnel of the need for referral, should this be deemed necessary.
- Beneficence vs maleficence: According to Beauchamp & Childress (2009), beneficence is compassion and taking positive action to help others. Thus, the researcher did not and will not use the information provided for non-academic purposes. The potential worth from the data gathered from participants far outweighed any potential discomfort, which in itself was addressed during the conduct of the study.
- The researcher ensured that no harm befell the participants and the information they provided was not used against them. The study was of benefit as it reconsidered how people view sexuality of people with disabilities, how awareness to the community and societies on disabilities and sexuality may be spread as well as reviewing anti-oppressive approaches for better service delivery to their service users.

## **4.9 CONCLUSION**

The chapter explored the research design and methodology and provided an explanation for the qualitative research approach as well as ethical considerations of the study.

## **CHAPTER 5: RESEARCH FINDINGS, ANALYSIS AND DISCUSSION**

### **5.1 INTRODUCTION**

This chapter presents the research data, an analysis thereof as well as an interpretation and discussion of the findings.

The reader is reminded of the objectives of the study which were:

- To establish what policies exist on sexuality in institutions
- To explore perceptions about the sexuality of people with disabilities from service providers
- To gain insight on how people with disabilities in institutions perceive their sexuality
- To explore challenges people with disabilities face when it comes to expressing their sexuality
- To explore service providers' understanding of sex education for residents in institutions.

The study was qualitative in nature, in order to get an in-depth understanding of the participants' perceptions on sexuality of persons with disabilities living in institutions. Participants were drawn from two residential facilities for people with disabilities in Gauteng. Two discrete sets of participants were used vis-à-vis that of service users and service providers. The two homes are 24 hour institutions; service users are under the care of nurses and caregivers who provide them with assistance in day to day activities which include, bathing, dressing, feeding and so on, depending on the disabilities.

Demographic information of the participants was gathered during the in-depth interviews and the focus group sessions. The interviews were tape recorded and transcribed by the researcher. Upon completion of the transcription, data was analysed and themes were developed accordingly. Where applicable and appropriate, findings from both these research instruments and respondent groups are presented together in order to present a comprehensive picture of findings. However, in some instances, it was necessary to present findings of both sets of participants separately.

**Table: 5.1: Summary of Selected Demographic Information for Service Users (People with Disabilities)**

Note: Names have been changed to protect anonymity of respondents

<b>Names</b>	<b>Age</b>	<b>Race</b>	<b>Gender</b>	<b>Disability</b>
1. Busi	27	Black	Female	Cerebral palsy & Intellectual disability
2. Gugu	38	Black	Female	Cerebral palsy
3. Sihle	44	Black	Male	Cerebral palsy
4. Vuyo	36	Black	Male	Cerebral palsy & Intellectual disability
5. Amy	32	White	Female	Cerebral palsy
6. Sue	41	White	Female	Cerebral palsy & Intellectual disability
7. Paul	37	White	Male	Cerebral palsy & Intellectual disability
8. Tom	42	White	Male	Cerebral palsy

The two residential facilities catered for different groups of persons-one with a Black dominated clientele and the other that was mainly white dominated. Those with African names are from the Black dominated residential facility, which will be referred to as Home A. English names were given to white respondents from the other residential facility, which is a white dominated, Home B.

All the participants were permanent residents at these facilities, which they called 'home'. As discussed in the previous chapter, the sample was purposefully selected to suit the requirements of the researcher.

There were two youths, who were between the ages of 27 and 32 whilst the other six were adults (above 35). The age selection of persons over 27 was deliberate as the study involved an investigation of the dynamics of sexuality.

**Table 5.2 Profile of Service Providers in the Study**

<b>Demographic Variable</b>	<b>Description</b>	<b>Number</b>
Gender	Male	2
	Female	6
Age	20-29	1
	30-39	3
	40-49	2
	+50	2
Race	Black African	8
	Coloured	
	White	
	Indian	
Marital status	Single	3
	Married	5
	Divorced	
	Widowed	
Disability status	Yes	1
	No	7
Position	Caregiver	5
	Manager	2
	Cleaner	1

The table 5.2 shows a summary profile of service providers who participated in the study. Altogether eight staff members from Home A and B took part in the focus groups, four from each residential facility.

The data from the focus group and interviews will be discussed concurrently, however, where there are different findings and themes, they will be separated. It was interesting to note that most respondents in the service providers group were black. Perhaps this is because there is a larger population of black people in South Africa than white, and therefore more black staff, a matter which may warrant future investigation.



## 5.2 THEMES AND SUBTHEMES

The research findings are presented below in the form of themes and sub themes, generated from the data gathered, supported by direct quotations from the interviews and substantiated by literature. These sections are set out according to themes and subthemes, consistent with the objectives of the study.

The following themes were identified: sexuality policy, privacy, sex education, attitudes and beliefs about disability and sexuality, relationships, reproductive and sexual health knowledge, sexual abuse and reproduction. From these main themes the following subthemes were identified, relationship between staff and residents, general views towards people with disabilities, life-long children, self-esteem, asexual and over sexual, intimacy or sexual relationships and relationships with non-disabled people. There were significant areas of overlap in some of the themes and sub-themes but these need to be kept separate to fully appreciate how they influenced the service user.

In this analysis the researcher will discuss findings not only in relation to the aims and objectives of the study, but also the theoretical frame and literature pertinent to the study.

## 5.3 THEME 1: SEXUALITY POLICY

This theme is related to the objective of establishing what policies exist on sexuality in institutions. Policies are guidelines that people and organisations use to help them address various issues. Sexuality policies in residential facilities are of utmost importance as they make sure people with disabilities are treated fairly and that the institutions run effectively.

Service providers exhibited limited knowledge on the existence and details of their institutions' sexuality policy. The majority of the participants, however, indicated the prohibition of unprofessional staff and residents relationships, which is basically public knowledge as it is part of the Employees Act in South Africa, in almost every workplace. A few responses that typified the findings were:

*“So far I do not have a proper policy, the residents can have a relationship but not with staff. We are yet to meet as a board to discuss it.”* (Home manager 1)

*“We have not put in place, but we encourage them to have healthy friendships.”* (Home manager 2)

These responses indicate the reluctance of service providers to establish policies pertaining to relationships in their institutions. This confirms Shakespeare (2000)’s theory that, sexual relationships were not on the agenda of institutions. Both managers from the two institutions indicated not having a sexuality policy, however, expressing a need to establish one.

There was also evidence of some uncertainty regarding sexual policy, as suggested in the responses hereunder:

*“I’m not sure, if they are allowed or not.”* (Caregiver)

*“They have relationships here, so I guess it is allowed.”* (Caregiver)

This could be a result of a lack of staff training on sexuality programs for the service users or that managers are not informing caregivers of such policy. If this is the case, then it is cause for concern as it is the caregivers who are likely to spend the most time with residents.

Table 5.3 depicts the duration of service providers at the residential facility. The majority of them have been working at the facility for more than two years, which is enough time for them to be accustomed to the policies and code of practice of the institution. Sexuality of persons with disability was barely on the agenda in these institutions, as they were generalising what they thought sexuality policy meant.

Lack of staff training, according to AOP underlines oppression as people, in this case of a minority group of persons with disabilities, are denied opportunities to learn about their sexuality and how to express it. The absence of sexuality policies in the institutions means that sexuality of persons with disabilities is not recognised. If it were, there would be guidelines and procedures on how service users should exercise their rights in terms of expressing their sexuality.

An interesting finding related to sexuality was fear that service users who have severe disabilities should not become parents as follows:

*“They are not allowed, for example those who are severely disabled cannot have children, residents like X cannot take care of themselves, what more a child? It will be a disaster.”* (Cleaner)

As indicated by the Cleaner, some residents cannot take care of themselves, it would be more difficult for them and the resident if they were to have a child at the institution. Although this is a reasonable concern, however, the researcher considers the establishment of sexuality policies to guide both service users and providers to address matters pertaining to parenthood and sexuality, to make for good service provision.

The following participant indicated that a resident should have a partner who also has a disability. Sakellariou and Algado (2006) too state this is a societal belief that people with disabilities should be with other people with disabilities. Again, this norm is discriminatory according to the Social Model of disability, as people with disabilities are labelled and defined by their disability. This is evident in the following quote:

*“It is a difficult one. I think it is there, residents can be involved but they should date each other. If it is an outsider they should also be disabled.”* (Caregiver)

Furthermore, as noted from the participant’s remarks, this type of discrimination has resulted in people with disabilities being denied or limiting friendships, relationships and/or a sexual life (Shutterworth & Mona, 2002).

Related to sexual policy, is the following theme of a lack of privacy for service users.

## **5.4 THEME 2: PRIVACY**

This theme was explored to reveal the privacy concerns of service users in respect of their sexuality. The livelihoods of persons with disability is said to be under the surveillance of their carers, thereby denying them rights to privacy. Hollomotz (2009) echoes this idea as he highlights that people with intellectual disabilities are denied their sexual rights and privacy. Service users’ privacy is inevitably invaded almost on a daily basis, as most need help with their daily routines. As discussed earlier, there is frustration regarding denial of people with disabilities’ right to privacy (Cuskey & Gilmore, 2007). To confirm this, service users had this to say:

*“Yes I have my own privacy but we share bathrooms with men, it is not that comfortable.”*  
(Busi)

*“It is there, but sometimes you are disturbed by caregivers or the cleaner, who knock at your door.”* (Gugu)

*"It is ok, but you can never be alone here."* (Sihle)

*"I share with someone, but it is ok."* (Vuyo)

*"There is no privacy here. We do have our own rooms, but hey no privacy at all!"* (Amy)

*"Yes I have my own space. I don't share my room with anyone."* (Paul)

*"Yes and no. What is privacy (laughs) they bath, dress me but its ok."* (Tom)

From the participants' responses it was evident that each resident from both institutions highlighted areas where they felt their privacy was invaded. Most indicated that there was no privacy, in as much as some had their own rooms. Also the fact that the majority were assisted with day to day activities like, bathing, toileting, dressing and so on, changed everything as one's body is naturally private. Tom's response is a reflection of a typical reality of some of the residents who have special needs, as caregivers assist residents with their daily personal hygiene routines which inevitably infringes basic privacy.

Vuyo indicated that he shares a room with someone, and that there is no privacy, a reality for most institutionalised people with disabilities. This points to the possibility as suggested by Gomez's (2012) that most people with disabilities may turn to masturbation due to a lack of privacy as they do not have a private place for sexual expression, which in turn may lead to them being labelled as oversexed or that they behave inappropriately.

Paul indicated that he has privacy, as he considers privacy as having your own space. However, other respondents like Gugu dispute this. She acknowledged that there is privacy but to a lesser extent as staff who come, do not knock, and this is an example of invasion of her privacy. These findings concur with Lofgren-Martenson's (2004) view that, people with disability often feel that their personal lives are invaded.

This lack of privacy for service users is a form of oppression as AOP theory highlights preserving the rights of the dominant group, in this case those with the disability at the institution. More so, Campbell (2003) highlighted that AOP embodies a democratic value system and is concerned with eradicating inequalities. The researcher understands that some residents share rooms due to various reasons for instance cost cutting or even severity of the residents' disabilities, but such practical problems do not mitigate against the privacy concerns expressed by residents.

The researcher hence notes respondents' concerns as real and valid. Kempton and Kahn (1991) also validate this concern of lack of privacy for people with disabilities in institutions and that, given this problem, it is impossible to obtain a private space for sexual intercourse for them. Lesseliers and Van Hove (2002) in their study of individuals with intellectual disability also conveyed participants' desire for sexual engagement but this was impossible due to lack of privacy.

On a follow up question regarding how best can privacy of service users be observed at the institution, many said that they would want privacy and staff should just respect their space. Responses hereunder support this:

*"I would be happy if caregivers knock before they come in our rooms."* (Gugu)

*"Its irritating at times, I think they should respect us. It's a two way street. There is a reason why the doors are locked."* (Paul)

As noted from the above extracts, service users lamented the violation of their private space. Even though most of the residences did not expressly state that they needed privacy for sexual activity, there were subtle hints suggesting such a need. One of the respondents had this to say:

*"I'm a grown woman I have needs...I have a chair (laughs) I have said too much already."* (Amy)

As noted by Adams et al. (2014) disadvantaged groups such as people with disabilities, feel that their pleasure is of little concern compared to that of others. This also lends credence to the AOP theory as previously discussed. Further, Amy's response can be classified under political factors of sexuality (Family Planning New South Wales 2013) in that she was unable to freely express her views of her own sexuality signaling oppressed sexuality.

More importantly, the participant does not seem to embrace self-pleasure as part of sexual expression or acceptable, which could be the reason why she did not feel confident to discuss her sexual concerns with the researcher. According to the flower model of sexuality, one's self-esteem and wellbeing is seen as being enriched or reduced by the interaction of experiences in the five areas of sexuality and influences from the outside. In the present case, external forces like negative attitudes of staff in the institutions towards the sexuality of people with disabilities affect their self-esteem which in-turn is harmful to their sexuality.

Another notable observation was that most of the caregivers were females as illustrated in Table 5.2 This suggested limited gender preference awareness as both homes have only female caregivers, who attend to both male and female residents. Sexuality according to World Health Organisation (2010), is influenced by the interaction of various aspects, such as biology, society, politics, religion, culture and so on. For that reason, culturally, a female is not supposed to see a male naked and vice versa. Hence, in as much as the staff is trained to conduct their work professionally, there is an element of de-gendering as noted by Chapel (2013) in Chapter 3. This aspect is also evidenced by sharing of bathrooms by both sexes at the facilities, which was confirmed by Busi.

The subtheme that follows hereunder discusses relationships that service users have with their service providers, this being is vital as there is a dependent relationship between the two, with residents being on the receiving end.

#### 5.4.1 Subtheme: Relationship between Service Users and Service Providers

The importance of this relationship is that it has an underlying tone of power and control. Service providers wield a certain level of power and control over service users. This puts service users in an inferior position and may not be able to share information on sexuality without prejudice. It was equally important for this study to ascertain the amount of time that service providers spent at residential facilities and whether this amount of time was sufficient for service providers to realise that people with disabilities have sexual needs. Also, the focus was particularly on the kind of relationships staff and residents have and whether there is exchange of information especially on intimacy, hence it is explored herein under the theme of 'privacy'. The following table, Table 5.3 presents the duration of service providers at their particular institutions.

**Table 5.3 Summary of service provider's duration at the residential facilities**

<b>Position</b>	<b>Period</b>
Home Manager 1	More than 5 months
Cleaner	5 years +
Caregiver	5 years +
Caregiver	2-4 years
Home Manager 2	5 years +
Caregiver	2-4 years
Caregiver	5 years +
Caregiver	5 years +

As depicted in the Table 5.3, five out of eight service providers had worked at the institutions for more than five years. Only the manager from Home A indicated being at the institution for less than a year.

Service providers were required to disclose the kind of relationship they had with their service users. All of the participants indicated that they have good relationships with the residents, the following being their responses:

*"So far so good, it is a professional relationship."* (Home manager 1)

*"I am used to them. I just learnt to be patient with them."* (Cleaner)

*"I am close to them."* (Caregiver)

*"It's a good working relationship."* (Home manager 2)

Responses shared by participants showed that, there were good working relations between service providers and their residents, as most indicated that they were close to the service users. This is quite reasonable considering the duration of service by most of the service providers at the institution.

Service providers were also required to explain if residents shared their intimate information with them, their responses being:

*"No actually, it is not my area, it's the social worker's duty."* (Home manager 1)

*“Yhuuu (exclamation of awe or surprise) shame they are so secretive, they do not share with us.” (Caregiver)*

*“No they do not.” (Caregiver)*

Evans et al. (2009) in their study of a West Ireland community of carers for people with intellectual disability and views of personal relationships and sexuality of service users, found that a significant percentage of staff were more likely to discuss sexuality with service users, compared to family members. This could be because the service users' family members may hold conservative attitudes towards their disabled relative instead of seeing the person with the disability as adult who has sexual needs.

Brown (1994) highlights the term “innocence paradigm” to describe how carers view people with disabilities. Evans et al. (2009) also revealed that both staff and family carers were not confident (albeit that some discussion did occur) about having sex-related discussions with service users. This aspect is also confirmed in the present research study, residents do not share intimate information with staff. However, a few service providers indicated that residents open up to them; they stated the following:

*“They do say (I have found a boyfriend) but I tell them not to bring someone at night or get pregnant along the way. It is difficult to take care of the residents themselves.” (Cleaner)*

*“Yes, some tell me about their desires regarding sex but I think most are shy to share such information with us. Maybe they fear to be gossiped.” (Caregiver)*

A lack of understanding of one's needs is the attitude most commonly experienced by people with disabilities. The response from one of the caregivers that some residents are reserved or secretive could be as a result of this, fear of being judged or being exposed or because of the restrictions placed on their sexual autonomy. Evans et al. (2009) argue that people with disabilities in institutions are reliant on service providers for knowledge, guidance and feedback.

It is possible that staff's experiences and beliefs influence their relationship and attitudes towards people with disabilities, which can potentially harm them as they infringe on their rights by imposing their own beliefs and attitudes. Servais (2006) too suggests that service users' sexual knowledge is obtained through the staff of these institutions. Hence, it is imperative for both parties to maintain close relations for the healthy sexual wellbeing of



service users. Sex education plays an important role in the sexuality of people, particularly people with disabilities as they may require extensive training to promote sharing of personal and intimate information. The following theme addresses this in detail.

### **5.5 THEME 3: SEX EDUCATION**

Tupper (2013) defined sex education as an instruction on issues relating to human sexuality including emotional relations and responsibilities, human sexual anatomy, sexual activity, sexual reproduction, reproductive rights, safe sex, contraceptives and so on. The inclusion of this theme is to meet the objective of investigating provision of sex education in institutions for people with disabilities.

As discussed in Chapter 2, people with disabilities are labelled and considered to have limited knowledge on sexual activity and also do not access sexuality related support programs. Service users were therefore asked if they were aware of what sex education meant. The participants were largely aware of what sex education meant, however, their responses revealed that they did not receive education on the subject at the residential facilities. The following responses prove that:

*“There is nothing much because no one really sat down with me regarding that. We need to be taught. I do know about condom-use to prevent STIs and pregnancy, but look I’m 27 now, I also have feelings I think such a program will help me make the right decisions.”* (Busi)

*“It is having an agreement of having sex. If someone touches your body without your permission, it is not acceptable. Also people must not sleep together without getting tested at the clinic.”* (Gugu)

*“It is difficult! But I think it is about condom-use, one should get tested and also their partner so that they know their statuses.”* (Sihle)

*“Pretty much what I did in high school. It is how to handle yourself when it comes to sex, how to protect yourself from diseases, pregnancy and deeper parts of your life than your body.”* (Amy)

*“It is self-explanatory I suppose. Basically its knowledge on how one needs to be aware of their sexuality.”* (Paul)

From what was asserted by the service users, sex education would play a pivotal role in their lives, unfortunately their views prove that they are not receiving it at the residential facility. Participants like Amy point out that she learnt about sexual health education at school, which suggests that service users did not receive such education at the institution. Clearly, sex education remains inaccessible for people with disabilities and this has resulted in them having little knowledge on how to practice safe sex, use contraception and prevent sexually transmitted diseases, as discussed by Galea et al. (2004).

Provision of sex education in residential facilities is of great importance in improving the sexual wellbeing of persons with disability. This theme met the study objective to explore service providers' understanding of sex education for residents in institutions. The flower model of sexuality provides sexual health guidelines that include sex education. A lack of it can extenuate inappropriate behaviour, like public masturbation as noted by Lindsay (2002).

In the present study, service providers admitted the need to have sex education programs for people with disabilities. However, the majority of service providers had limited knowledge on what sex education entailed which needs to be addressed through policy interventions. Only a handful of service providers had an idea of what sex education was and this was reflected in the following responses:

*"I have not explored that area but I think it is important to protect them from diseases and bad relationships"* (Home manager 1)

*"Sex education, what does it mean though? It's a bit difficult. They can have sex, you cannot deny them that, but they should be taught all the basics because as you know some of them are not ok mentally"* (Caregiver)

There is a myth that information and education about sex will encourage inappropriate sexual behaviour (Shutterworth & Mona, 2002). This is asserted in the response hereunder:

*The program sounds good but here (Name of Home) it might promote promiscuity because some of them love to engage in sexual activities...I can imagine how they will do it, exchanging partners. It will be a disaster let us be honest its better they stay as they are."* (Caregiver)

The above submission resonates with the observation of Gomez's (2012), who submits there is a general reluctance to provide sexual health programs and support for people with disabilities in institutions. Gomez goes on to say that service providers fear that it may

encourage sexual promiscuity and inappropriate behaviour. In addition, the caregiver opined that it is preferred to prohibit people with disabilities from engaging in sexual activities because in the eyes of the caregiver, people with disabilities may not be able to handle relationships. Also, it is feared as noted by Gomez (2012), that the provision of sexual health education can open doors for sexual abuse. This is because people with disabilities are viewed as vulnerable, an oppressive view as per AOP. Further, there is a misconception that people with intellectual disabilities and autism, may not comprehend the complexities and dynamics of intimacy or connect with their partner in profound relationships. For this reason, service providers may try to protect their residents from being susceptible to such intricacies. The researcher wonders if evidence on this point should not precede such a view.

However, these fears although they may be true, sex education for people with disabilities should be encouraged in order to capacitate the service users. Of course, there has to be proper due diligence on the mental capacity of particular service users in order to ascertain their ability to comprehend sex education. AOP challenges structures of oppression and invokes critical consciousness, in this case it would challenge service providers in institutions to reconsider oppressed views on the damage perceived to emanate from sex education and hence allow for the provision of sexual health education. This is directly related to the issue of reproduction which is part of sex education and this is the subject of discussion below.

#### 5.5.1 Subtheme: Reproductive and Sexual Health Knowledge

Access to and control over use of contraception is considered a fundamental human right according to Article 23 of the United Nations Convention on the Rights of People with Disabilities. People with disabilities have the right to marry and find family. The World Health Organisation (2009) women with disabilities do not have the choice to decide if they want to be in a relationship or not and whether they can give birth to children or not. Also forced sterilisation and abortion is practised. This is evidence of coercion which is oppression towards people with disabilities. The researcher's objective on this theme was to gain insight on how people with disabilities in institutions perceive their sexuality, in terms of the participants' awareness of their reproductive sexual health. Participants (service users) were asked about their knowledge about contraceptives and if they have used them before. Extracts from the interviews are as follows:

*“It is prevention against pregnancy. I get injection at the clinic even though it makes me fat...it assist me because I do not menstruate because I used to have period pains.” (Busi)*

*“... I use the injection it helps reduce my feelings. If you do not want injection, there are pills and condoms to prevent STIs.” (Gugu)*

Busi’s response was an indication that some people in residential facilities were required to use contraceptives that they did not have knowledge about. Harris (2005) highlights that most the residents do not know why they go through sterilisation. Busi indicated that, she was administered an injection so that she did not menstruate. She assumed this injection helped her with period pains. This demonstrates a level of deception and lack of transparency as well as misinformation. Gugu was more aware of why she was having the injection, indicating that it reduced her sexual urges. One wonders what such a realisation does to an individual in relation to frustration and prevention of individual freedom.

Responses of residents from Home B were slightly different from Home A. This is reflected below:

*“... It’s a choice so I tell the caregiver I know my dates for the injection.” (Amy)*

*“I have used them before to prevent pregnancy and STDs. I remember during the time I was admitted here, they asked me if I wanted to use contraceptives ...my tubes are tied so I am pretty much safe.” (Sue)*

The above responses show how the above residents were aware of their right to consent and had knowledge about the purpose of using the contraceptives unlike residents from Home A. This may be a small victory but it is significant, in that individual freedom is herein not compromised.

The male participants from both institutions however, indicated the usage of condoms as a way of preventing diseases and unwanted pregnancies. Their responses are hereunder:

*“Its prevention against STIs and pregnancies. I have used protection before.” (Tom)*

*“It’s for ladies to prevent against pregnancies, but to be safe people should use condoms to also prevent against HIV.” (Vuyo)*

This difference in the responses of the sexes demonstrates how women are susceptible to risks than men.

The theme that follows discusses misconceptions that the general public has about people with disabilities. It is a critical focus of this study, as the researcher aimed to demystify some misconceptions in several related areas.

## **5.6 THEME 4: ATTITUDES AND BELIEFS ABOUT DISABILITY AND SEXUALITY**

The sexuality of people with disabilities is generally associated with negative attitudes and prejudices (Andersson, 2010). This theme aims to address the grey colour of the flower model of sexuality, which is the darker side of sexuality, mainly exploitation and oppression of the weak. Zastrow (2010) refers to persons with disability as a disadvantaged and vulnerable group as they occupy marginal positions in society (Anderson & Kitchin, 2000). As a result these persons are labelled and discriminated against. AOP, as used by Campbell (2003) supports the importance of encouraging, supporting and focusing knowledge and perspectives of those who have been marginalised and combining these perspectives into policy and practice. The following subtheme is on how people with disabilities think society views them.

### **5.6.1 Subtheme: General Views towards People with Disabilities**

As already outlined, people with disabilities are subjected to a number of stereotypes and discrimination. Anderson and Kitchin (2000) argue that they are portrayed as abnormal or freaks of nature. This theme is related to the general aim of this study, to unveil myths and misconceptions towards people with disabilities. The researcher sought answers from people with disabilities themselves as they have firsthand experience when it comes to being pigeon-holed or misunderstood. The following sentiments were shared:

*“They speak badly about us. We are not treated as other human beings, and people on wheelchairs like me, are discriminated against, because they also think I have a mental disorder” (Busi)*

*“Firstly, people stare a lot at me. I would say it depends on one’s experience, they will have a different view when they have an encounter with someone who has a disability. Secondly, people have different views when they see a person on a wheelchair they think we are crazy...like mental disability of which I do not have my sister. I also think that*

*people see us as a bother or we need to be pushed of which that is not always the case.”*  
(Sihle)

*“I do not know why people always stare, it is uncomfortable, maybe they will be seeing an alien”* (Paul)

The researcher has noted some disability discrimination from people with disabilities themselves, discriminating other disabilities which they regard and consider more severe than theirs. The common trend was for people to generally regard intellectual disability as mental illness. As previously discussed, people with mental illnesses were regarded as menaces or a burden to society (Harris, 2005). Studies have shown that negative attitudes and discrimination as previously discussed, are worse towards people with mental illnesses. People with mental illness can have disturbances in many different functions. For instance, their senses, thinking, feeling, reasoning and may be violent to others and themselves. As a result, people tend to shun them as they are labelled as crazy and aggressive.

In this regard, responses from the participants show how people with intellectual disability did not like to be labelled as mentally ill or “crazy.” Also there was fear of mentally ill people becoming aggressive, and even though this may be true, it is not always the case with all disabilities. This labelling and discrimination is due to poor understanding about these disabilities.

The medical model views people with disabilities as sick (WPRPD, 2015). This was supported in the study as follows:

*“They see us differently since we are different from them. Some think we are sick or in pain, some respect us but what’s painful is that people do not understand us, they are afraid of us.”* (Gugu)

Gugu’s thoughts correspond with Samowitz’s (2009) argument that people with disabilities seem to be perceived as ill or tragic victims. Sihle also highlighted that he dislikes assumptions that wheelchair users always want to be assisted, for instance, being pushed.

*“They are afraid that our disabilities are contagious even though some are friendly like our volunteers.”* (Tom)

Tom’s response shows how non-disabled people fear disability. He highlighted that, people are afraid of them because they fear the disability is contagious, which could be as a result of lack

of knowledge on the disability itself. On the other hand, the participant expressed some relief with the fact that there were some volunteers at the institutions who were friendly. This clearly shows that people who are sensitised to disability by working with them, may be more accepting and understanding of the person's disability than those who are not. Infantilisation of people with disabilities is one of the reasons why their sexuality is viewed as taboo or deviant. The subtheme that follows discusses this subject in detail.

#### 5.6.2 Subtheme: Life-long Children

Assumptions are that persons with disability are entirely incapable to live their lives without full time care of their carers and has resulted in them being infantilised. Thus, opportunities to form intimate relationships are close to none as they are considered as children. Also, restrictive policies for sexual expression are as a result of people with disabilities being viewed as vulnerable and as children. This is evidenced by most of the service providers who were interviewed, referring to their service users as their children, even though the residents are all adults. The following extracts validate this notion:

*"...we have a good relationship. You know I treat them just like my own kids. I love them shame"* (Caregiver)

*"They can behave like children sometimes. (Name of resident) when she is angry she does not want to be bathed, she can even take off her clothes. But we are used to them so we understand them."* (Caregiver)

Brown (1994) similarly, refers to this as the innocence paradigm, that people with disabilities are as innocent as children. Most of the service providers from the selected sample were below the age of fifty years and so were the service users. One of the caregivers mentioned that the residents can often behave like children. This may be as a result of their mental age, which does not correspond with their chronological age due to intellectual or developmental disabilities. This results in a reduced ability to survive autonomously, impaired social functioning which begins before adulthood with lasting effect on development.

Consequently, as described by the caregivers, the service user may undress when she is upset, may be because of poor problem-solving skills, which in actual fact has nothing to do with one's physical growth. Likewise, people with cognitive or intellectual disability may have a mental age of a ten year old but their physical bodies is of an adult. This is evidenced by bodily

changes, puberty, and menstruation in women. Thus service providers should consider them as adults with adult needs as they are indeed grown-ups.

The flower model of sexuality represents human sexuality as it grows throughout people's lives. Therefore, in order for people with disabilities to be able to tap into their sexuality, there is need for service providers to detach themselves from being overly protective.

Infantilisation of people with disabilities was common. This was understandable given that service providers are the ones who play the parental role as they are primary caregivers of the service users. However, duty of care by service providers can actually hinder service users from expressing their sexuality. In as much as service users may have the intention of protecting service users from getting hurt or abused, by preventing them from having romantic and intimate relationships, they will be depriving them from their basic freedom and rights to sexual health.

McVilly et al. (2006) point out that prohibitive environments in which service providers and/or family members uphold the belief that people with intellectual disability are external children, restrict their access to social opportunities. Such practices are oppressive and demeaning to persons with disability.

### 5.6.3 Subtheme: Self-Esteem

According to Jahoda et al. (2006) people with disabilities, particularly, intellectual disability, may have few friendships and they can be lonely. The flower model of sexuality demonstrates that one's esteem encompasses one's self image, size, shape, physical disability and it affects one's sexual health (Adams et al. 2014). One's self-esteem is vital when it comes to healthy sexuality. Self-esteem is the fourth need in Maslow's hierarchy of needs. Scholars like Heydari, Mashak, and Darvishi (2009) and McCabe and Taleporos (2003) assert that people with physical disabilities have a lower self-esteem concerning their sexuality, due to their physical appearance. Internalised 'ableism' as a consistent theme throughout interviews with service users. For example Vuyo described feeling ineligible and undesirable for relationships stated:

*"It's difficult for me, maybe because I am disabled. There are so many girls who pass at the gate but they do not even look at me."* (Vuyo)



Adam et al. (2014) note that there is an increasingly obsession with looks and appearance, and that what one looks like, is what they deserve. Vuyo's quote above proves Adam's school of thought. Vuyo thought that he did not get attention from girls because he has a disability and is a wheelchair user. Gomez (2012) also concurs with this notion, of people with disabilities being perceived to be less desirable than able-bodied people. As a result, they may feel unappealing and will not be in a position to attract a sexual partner. Vuyo, like any other person with a disability, may view himself as ugly and sexually incompetent, hence he may stay single for the rest of their lives. This assertion is quite true as discussed below:

*"I easily get jealous, I am scared of being lied to ..."* (Amy)

*"...They should choose, but if they date a non-disabled person they become very jealous, so it is better if they date a disabled person."* (Caregiver)

In addition to feeling incompetent and unable to attract a partner, there seems to be some sentiments of possessiveness in the responses above. Amy indicated that she easily gets jealous an attribute that the caregiver also highlighted. This could be due to the fact that if a service user is to be in a relationship with someone who is not from the residential facility, the distance of being apart and not knowing what their partner is doing may cause anxiety or insecurity. Low self-esteem, could also be as a result of feeling inferior to able-bodied people, because of physical appearance. Hence, they end up feeling vulnerable and insecure with fear of losing their partner to an able-bodied person.

The following sub theme discusses over misconceptions on people with disabilities' hyper sexuality and asexuality.

#### 5.6.4 Subtheme: Asexual versus Over sexual

Service providers highlighted that people with disabilities were oversexed. They were all in agreement with this sentiment and none of them raised the issue of asexuality. The following responses clarify this:

*"They love it tjo!"* (Home manager 1)

*"You know what, their feelings are too much!"* (Caregiver)

*“They crave for it every day that’s the truth! Even when bathing them some always have erections...”* (Caregiver)

*“It is true. They wish they had some, especially those who are born with disabilities...because I think they have not done it. It is a pity because they are old enough shame!”* (Caregiver)

The above responses clearly demonstrated that service providers thought that people with disabilities loved sex more than those without disabilities. This distinction was borne out by them (non-disabled community/staff) distancing themselves from people with disabilities. Their sentiments suggest residents had a peculiar physical disposition. One of the caregivers raised an issue from the above extracts, of a service user having an erection when he was being bathed. This could be as a result of sensational touch that can arouse the resident physically which is biologically normal and therefore does not necessarily mean that the resident had a high sexual drive or was hyper-sexed.

When the service providers were probed to validate their responses on hyper-sexuality of the disabled person, they could not justify this claim, however one said:

*“We grew up people saying that and it’s kind of true...even that (Name of an ILSEN School) across the road, the children there are a disaster they even do it in the toilets!”* (Caregiver)

This quote, is an indication that the “people” that the caregiver was referring to, belong to a society in which myths on sexuality and disability still exist.

There seem to be conflicting views with regards to sexuality of persons with disabilities as being either asexual, uninterested in sex or are sexual monsters, unable to control their sexual drives and feelings. It is an unfortunate myth that people with disabilities are regarded as asexual as people tend to believe that their physical disabilities may contribute to this. However, the service providers alluded that people with disabilities are hypersexual, even though their perceptions were based on assumptions and not evidence.

When service users were asked about societal perception of them being over- sexed, they were dismayed as indicated below:

*“Haa-aa that’s a difficult question, but I don’t see a problem that people love sex. It is not true from my point of view. They speak badly about us...”* (Busi)

*“It’s not true, we just want to be loved and given attention just like everyone else.”*  
(Gugu)

*“It’s not only people with disabilities who love sex, even non-disabled people. There is no difference when it comes to sex. It’s people’s perception but it does not necessarily mean it’s true.”* (Sihle)

When reviewing the responses one may be able to distinguish how people with disabilities feel about these stereotypes regarding their sexuality. Tepper (2000) too found that that society’s general perspectives on sexuality of people with disabilities are predominantly negative. Waxman and Finger (1991:1) add eloquently in this regard that people with disabilities “... may well be more concerned with being loved and finding sexual fulfilment than getting on a bus!”

As far as equality is concerned, sexual rights of persons with disability should also be considered. From the interviews that the researcher conducted, service users longed for romantic relationships.

The findings herein suggest contradictory thoughts from service providers towards the sexuality of their service users. On the one hand they perceived people with disabilities as hyper-sexed, whereas on the other hand they did not have policies to regulate sexual relations at the facilities, because this was perhaps seen as unwarranted. This demonstrates how sexuality of persons with disabilities is not recognised, is misapprehended and not catered for. Assumptions on asexuality of persons with disabilities can be as a result of severe disabilities, such as multiple sclerosis and spinal cord injuries. These disabilities according to Morris (1991) may cause sexual dysfunction, for instance problems with orgasm and arousal. However, not all disabilities can cause sexual dysfunction.

The following section discusses relationships of the participants and the challenges they face when it comes to dating.

## **5.7 THEME 5: RELATIONSHIPS**

The flower model of sexuality illustrates the importance of emotionally significant relationships to one’s sexual health. Therefore this theme will show how people with disabilities view themselves as sexual beings. According to Maslow (1954) humans need to

love and be loved, both sexually and non-sexually, by others. Hence, dating was explored in the study. The following sub theme discusses the dating status of service users.

#### 5.7.1 Subtheme: Dating

There are societal expectations that people with disabilities should be with people who also have a disability (Sakellariou & Algado, 2006) and when one has a non-disabled partner it is viewed as odd. This sub theme of dating met the objective to investigate perceptions of persons with disability as sexual beings. The subsequent table 5.3, shows people with disabilities' current relationship statuses, the duration of their relationships and the disability statuses of their partners.

**Table 5.4 Summary of People with Disabilities' Relationship Statuses**

<b>Name of service user</b>	<b>Current marital status</b>	<b>Duration of prev. relationship</b>	<b>Disability status of partner</b>
Busi	Single	Short while	Cerebral palsy
Gugu	Single	1 year	Could walk-Cerebral palsy
Sihle	Divorced	7 years	No disability
Vuyo	Single	Couple of months	On wheelchair
Amy	Single	Not very long	Cerebral palsy
Sue	Single	Years	Head injury-on wheelchair
Paul	Single	Once off	Cerebral palsy
Tom	Single	6 years	She had my disability

As depicted in table 5.4, all eight participants except for one, indicated that they dated partners who had a disability of some sort. This affirms the idea that people with disabilities should be with partners who also have disabilities. One of the participants indicated the following:

*"...personally I want a normal person who has two legs, I don't want someone like me."*  
(Busi)

This is an example of preference, just like everyone else who chooses a mate. The researcher believes that the reason behind participants having partners with disabilities could be because of availability and mobility concerns. Gomez (2012) likewise offers the reason for this, that people with disabilities who live in institutions have limited access to opportunities to interact and socialise with others or form intimate relationships. Again, according to Maslow's theory, this unexplored aspect of life leads to an imbalance.

Sexual activity and romantic relationships form part of one's sense of belonging which are aspects of sexuality. Consequently, one's sexuality is an important part of the personality of every human being and cannot be separated from other aspects of human needs.

The researcher appreciates differences in the severity of disabilities and acknowledges that participants may have had the power to verbalise choices regarding relationships. Perhaps, such participants who can express their needs should be given the chance to exercise their right to certain partners, as not allowing for this is tantamount to oppression. This leads to the following discussion on challenges faced by persons with disabilities in this regard.

#### 5.7.2 Subtheme: Intimacy or Sexual Relationships

The subtheme required participants to offer ideas and thoughts on partners and relationships. It also focused on challenges participants had in forming intimate relationships. Wright, Wright, Perry and Foote-Ardah (2007) propounded that forming and keeping intimate relationships is an expected during an adult life in most cultures, yet persons with disability especially intellectual disability, are sexually alienated. This aspect was explored herein.

The flower, according to the flower model of sexuality, represents human sexuality and it grows throughout the human life cycle (Adams et al. 2014). As previously discussed, Maslow's hierarchy of needs recognises sex as a physiological need, which service users disclosed as a difficult area at the institutions. Responses were as follows:

*"There is no one who has approached me, I wish there was someone who can love me the way I am. Also I get discouraged by people, the caregivers always advise me not to get pregnant since I am on a wheelchair. They worry about me, how I will take care of my family, cooking, ironing which is difficult since I am disabled."* (Busi)

*“The rules, they are prohibitive even though there are people who are interested in me.”*  
(Gugu)

*“Where can I get one, we are closed up! You see the same faces all the time, it’s like they are my brothers...”* (Sue)

*“Mobility, I want to go to movies, the mall, meet people but it is not happening.”* (Paul)

The researcher gathered that respondents did not necessarily want to be in relationships with their fellow residents at the facility as they felt that they had become family hence, did not regard them as potential partners. Sue indicated that they felt closed up, hence that they were limited in forming new relationships. The participant also indicated that the male service users were like brothers to her, which is understandable as they live together at the institution, and were practically the only family they had. Gomez (2012) and Shutterworth and Mona (2002) agree that people with disabilities have limited access to opportunities to interact and socialise with other people, which is essentially oppressive as per the AOP frame of the study.

Mobility had a deterrent effect on people with disabilities as indicated by most of the participants who were wheelchair users. This confirms the findings of Shakespeare (2000) that people with physical disabilities, particularly wheelchair users may find it difficult to form relationships due to mobility and access issues. AOP seeks to understand such barriers as they are limiting and inconsiderate of the rights of the individuals concerned. In this regard, Sue highlighted that service users were “closed up” meaning that she was not given the opportunity to go out and refresh and meet new people.

Gugu, however said there were people who were interested in her but due to prohibitive rules at the home, she could not form intimate relationships. A similar pattern of boredom and frustration was expressed by service users when they indicated that they felt trapped at the facility. Dominelli (1998) argues that AOP seeks to emancipate the dominated group which had been subdued by structural inequalities such as in this instance being seen as “closed up” at the facility. Wilson and Bereford (2000) note that AOP seeks to assist people in their desire to reverse the positions they are in.

Service users were interested in meeting new people but, they struggled to meet them as the residential facilities had restrictive policies which prevented freedom of movement and association (White Paper on an Integrated National Disability Strategy, 1997). The flower model of sexual points out that when one’s sexuality is restricted (as in limits to free

movement), it can be stunted (Adams et al., 2014), a concern that could have been a real experience for service users, given the findings of the present study. In this regard Blauner (2001) asserts that oppression includes depriving people of a way to make a living, to participate in all aspects of social life. This includes people with disabilities living in institutions being allowed the opportunity to go out and meet people and forming friendships and relationships.

Service users were also asked what kind of challenges service users faced when it comes to dating. Their responses were as follows:

*“That one is tricky, personally, I do not want them to date.”* (Home manager 1)

*“There used to be residents who dated back then and got each other pregnant but due to the Institution’s policy they had to be let go. Some are just used for sex so I guess to answer your question they should just stay friends it is much simpler that way.”* (Cleaner)

*“The problem is, they do not tell us, so we do not know. I think they like to date but some are shy. But we have one guy here who has a mental disability, he is very open...he even asks us on dates...”* (Caregiver)

*“(Name of resident) X had a boyfriend, but, he was not right for her because you could see that he just wanted to play with her...it’s a challenge also because they want people who do not have disabilities.”* (Caregiver)

*“Some people do not actually love them, they just want to use them, which I why I prefer they date on their own.”* (Home manager 2)

Service providers’ attitudes towards dating of people with disabilities were generally negative, with most highlighting that they were taken advantage of and used. Others indicated that it was better if they were to have relationships with those who also had disabilities as those without disabilities may not love them. This finding was discussed earlier as well. Such negative perceptions are discriminatory.

According to Section 9 (2) (3) of the Constitution of the Republic of South Africa, everyone is equal before the law and equality should be exercised. This includes the full and equal enjoyment of all rights and freedoms and thus there should be no discrimination against one’s gender, race, age, sexual orientation, disability and so on (Integrated National Disability

Strategy, 1997). The researcher maintains that such prohibitive and conservative attitudes towards people with disabilities regarding romantic relationships or expressing themselves sexually is an oppressive practice which needs to be addressed.

The next subtheme addresses concerns pertaining to people with disabilities dating non-disabled people.

### 5.7.3 Subtheme: Relationships with non-disabled people

An inquiry was made on service providers' views on residents having partners without disabilities. A few respondents indicated that they did not see anything wrong with persons with disability having partners without disabilities. They had this to say:

*"I think if someone wants to have a relationship with a non-disabled person, it is okay. In my case (as you can see) I have polio but my girlfriend is not disabled."* (Home manager 1)

*"They can, I have a nephew whose wife does not have a disability and are happily married with children. But come to think of it, I think it is better on their own; wheelchair users should date each other. This is because my nephew is working his mind functions well unlike our residents."* (Cleaner)

Participants who had knowledge on disability were more accepting of people with disabilities having partners without disabilities. This is mainly because they had firsthand experience of people with disabilities, for example, the home manager had a disability and the Cleaner had a relative with a disability. Similarly, people who did not know about disability may have had preconceptions which are generally negative. Responses from most service providers were that people with disabilities should date each other. The following responses echo this notion:

*"They can but it is a challenge. A non-disabled person can cheat on the resident even though disabled people love those without disabilities."* (Caregiver)

*"I don't think it is right. They want those without disabilities so that they get assistance."* (Caregiver)

The above also confirms Esmail et al.'s (2010) view that there is an overwhelming fear of being a caregiver rather than a partner, when a non-disabled person is in a relationship with someone



with a disability. The reasons for this view was explored. Service providers saw themselves as emotionally stable and less vulnerable than people with disabilities, as noted below:

*“It is not right, if they can cheat on us who are not disabled, what more those with disabilities. It will be worse because they will be used and left alone.”* (Caregiver)

*“It is their choice when it comes to love. They should choose, but if they date a non-disabled person they become very jealous, so it is better if they date a disabled person.”*  
(Caregiver)

*“They can, but they will get heartbroken and even get abused, men out there are cruel!”*  
(Caregiver)

The majority of the participants indicated that people with disabilities were more prone to abuse and ill-treatment in the relationships. They also highlighted infidelity as one of the reasons why people with disabilities should be with people who also have disabilities. Service providers appeared to be keener on residents being with other people who have disabilities because they may understand each other better. Service providers were more inclined to service users not to be in relationships because they wanted to prevent them from being hurt emotionally or sexually abused. The following theme addresses sexual abuse in detail.

## **5. 8 THEME 6: SEXUAL ABUSE**

Sexual abuse or assault of people with disabilities was an essential component of this study as it relates to sexuality even though it is sadly the dark side of sexuality according to Adams et al.'s (2014) flower model of sexuality. According to Campbell (2003), oppression is when one social group takes advantage of another social group, either knowingly or unconsciously. It is often the result of powerful people or social forces exerting power over the weak. Sexual violence against people with disabilities is even more problematic and this is because such persons are considered weak and vulnerable.

Aggressors take advantage as the victims may not report the matter, particularly because of their disability. For instance wheelchair users may struggle to access the nearest police station or those with a mental or cognitive disability may not comprehend or remember the incident as they should. The theoretical framework of this study allows for the eradication of oppression against people with disabilities.

Andersson (2010) argued that the only way people with disabilities experience sexual intimacy is through rape. Additionally, abuse is extremely common in people with intellectual disabilities (Carmody, 1991; McCarthy & Thompson, 1997).

The following quotes authenticate this claim, where participants were asked if they were approached by someone for sexual favours.

*“Yes when I was young I almost got raped. I reported the person to my aunt.”* (Busi)

*“Yes someone did ask for sex from me, he did rape me...haaa he never got arrested.”*  
(Gugu)

*“Yes since I was like 15 but I really do not want to get into detail ...”* (Amy)

*“Yea it was a long time ago before I came here, I was young he actually forced me but I never reported him ...”* (Sue)

Women with disabilities appear to be more prone to abuse than their non-disabled counterparts, presumably because of their disability as it makes them more vulnerable. The researcher also believes that accessibility to sexual health education is limited for people with disabilities as most of them do not have the opportunity to go to school due to their disabilities. Table 5.1 shows that some of the participants have intellectual disability, thereby limiting these participants' chances of receiving formal education.

Family members too, may withhold sexual education conversations with their child or family member with a disability as they may feel that they need to focus on their disability. This is discussed by Nelson (1995) and Hallum (1995) who state that parents often avoid talking about sexuality with the child who has a disability because they do not believe that the child will ever have a sexual relationship. In the end this is detrimental as they may end up being violated sexually because of a lack and/or limited access to resources. According to United Nations International Children's Emergency Fund (2006) this has adversely resulted in a number of crimes committed against people with disabilities.

The researcher suspects that the reason service users are not keen on forming new relationships could be due to history of abuse in their childhood, as traumatic life events such as sexual abuse can be circular in creating ongoing life problems. Amy, during the interviews could not share further with the researcher, as such experiences were unpleasant. Adams et al. (2014) also attest to this, that childhood abuse can leave life long and damaging scars on one's ability to form

positive sexual relationships. This is an important point for service providers to note, if they are to enhance the lives of people with disabilities. This may include extensive counselling or therapeutic groups in case of post-traumatic experiences to foster positive sexuality.

Women indeed are more prone to sexual assault and abuse than men. Below are quotes from the male participants:

*“No but I have approached some.”*(Vuyo)

*“No I have never been in such a situation.”* (Paul)

*“Hahaha that would be interesting but not yet.”* (Tom)

None of the male participants indicated that they had been sexually abused or approached for sexual favours. Only the female participants had been abused at least once in their life time. The Disability Act of South Africa postulates that women and children with disabilities are more often subject to various types of violence, particularly sexual violence, and are more vulnerable to HIV and AIDS transmission (Department of Social Development, 2008).

This is evidenced by the above quotes from the eight participants, all four women were sexually abused during their childhood. Furthermore, research shows that women with intellectual disabilities are even more vulnerable to sexual abuse, as they are likely not to resist and if they report the abuse, they are less likely to be believed (Sullivan, 2000) as was found in the present study as well. This also confirms Andersson’s claim that the primary encounter of sexual activity for people with disabilities is usually through rape. This was demonstrated by the female participants who were sexually abused when they were still young. On the contrary, the males in the study had not experienced any sexual favours in their life time, with Vuyo admitting to rather have approached others for sexual favours.

Service providers from Home A indicated two incidents from the past of sexual abuse that occurred at the institutions. They stated the following:

*“From what I heard, there was an incident, which involved a staff member who was a security guard and three female residents. No proper follow-ups were done because when the three residents were asked, one admitted to having called him to her room, the other one was involved in a relationship with the security guard. I’m quite not sure about the third resident...but they ended up firing the security guard”* (Home manager 1)

*“Yes, there were prisoners who had come to clean up the yard here, one got in in one of the resident’s room and slept with her. She ended up getting an infection, investigations were done but there were no charges if I remember correctly, apparently X (name of the resident) was the one who had invited the prisoner to her room.” (Caregiver)*

The responses of service providers shows that there is lack of firm policies at the institution from addressing the problem, for instance regarding policies allowing visitors in the rooms of service providers who are not family, or staff and resident relations. Also, establishing a sexuality policy may assist service users to know boundaries with regards to sexual expression. As stated above, one of the residents was involved in a relationship with the security guard, which may have been considered “acceptable” at the facility.

Responses provided by the service providers indicate that sexual intercourse was consensual hence it could not be defined as sexual abuse, as the residents were the ones who invited the ‘perpetrator’ in their rooms.

The home manager from Home B had this to say:

*“...I can yes and no, because it was consensual. One of our caregivers caught the residents in the act... when we asked them, the female resident she said she was raped but the male resident said they had agreed to sleep together. (Home manager 2)*

From the response given by the Home manger above, the female resident must have been ashamed to admit that the sexual activity was consensual, but felt embarrassed. This finding is also similar to Lesseliers and Van Hove’ study (2002) of forty-six individuals with intellectual disability in Flanders, Belgium. The majority of the respondents, according to the authors, explicitly expressed a desire for sexual engagement but were discouraged by their caregivers. They indicated that caregivers disapproved of their desires and many experienced guilt and shame about their sexual feelings.

Similar results were yielded in this study; the residents indeed might have enjoyed engaging in the sexual activity however, felt ashamed because of condescending attitudes from service providers, which, ultimately reduced their self-esteem and sexual health. Likewise, Wolfe (1997) also argues that sexuality of institutionalised people with disabilities is repressed and overt sexual expressions are punished. In this case, punishment maybe in the form of being questioned in a disrespectful manner or negative attitudes generally towards the service users.

Such negative attitudes are oppressive as people with disability may fail to express their sexual needs.

A related theme which has emerged and is of concern is the reproduction of people with disabilities, discussed hereunder.

## **5.9 THEME 6: REPRODUCTION**

Sexual health encompasses a lot of factors, which include, social relationships (families, marriages), sensuality, and intimacy and sex (Adams et al., 2014). Article 9 of the UNCRPD (2006) advocates for the equalisation of opportunities for persons with disability and promotes their full participation in family life. Service providers and carers for persons with disability are encouraged to ensure that they promote the right to personal integrity and that laws do not discriminate them with respect to sexuality, relationships, marriage and parenthood. Reality, based on findings in the present study are a far cry away from this ideal.

Most people with disabilities have aspirations to have children and/ or intimate relationships, however cannot exercise this right as they are living in institutions. The following quotes exemplify this sentiment:

*“I wish I could find a man and have kids. I also want to go to school so that I can have a bright future.”* (Busi)

*“I want to have someone who can love me the way I am. I wish to have children and take care of them.”* (Gugu)

*“I wish one day I can move out to my own house with my wife and two children, a boy and a girl.”* (Vuyo)

The majority of the service users aspired to marriage and children in the future, and most associated marriage with happiness and freedom. Vuyo’s sentiments validates this, as he said that he wishes to move out and start his own family. Reproduction of people with disabilities according to Cuskelly and Bryde (2004) is discouraged, especially for people with mental illness and cognitive disabilities. This is a sad reality, as almost all the participants indicated a desire to have a family. The following participant indicated this as per the following quote:

*“I was adopted, I do want to have a man, get married, but I do not want to have children.”*  
(Amy)

Service providers had this to say regarding the reproduction of people with disabilities:

*“They are not allowed, for example those who are severely disabled cannot have children, residents like X cannot take care of themselves, what more a child?”* Cleaner

Wolfe’s study (1997) in Virginia of special education teachers and administrators about sexuality and disability similarly found that sexual relations were regarded as inappropriate and that people with disabilities should be sterilised. There are genuine concerns raised by the service providers as some disabilities are severe and require one to be cautious as it may endanger the mother as well as the baby.

A possible reason why people with disabilities being discouraged to have children is that there are misconceptions about them being likened to children as discussed in Section 5.6.2.

## **5.10 CONCLUSION**

The samples chosen were from two institutions for persons with disabilities in Gauteng, South Africa. Residential facilities, Home A was black dominated and Home B white dominated. However, experiences and perspectives of the participants were generally similar with minor differences. The trustworthiness of the data was established as the information gathered through the in-depth interviews and focus group was both from people with disabilities themselves and their service providers.

Primary concerns in the findings were of service providers working with people with disabilities did not know about, or believe there is a need for reproductive and sexual health services for their clients. Both institutions shared similar challenges when it came to their sexuality, particularly, prohibitive environments, a lack of privacy and misconceptions around their sexuality. These concerns will be summarised in the next chapter in a systematic manner.

## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS**

### **6.1 INTRODUCTION**

The main purpose of this study was to investigate qualitatively the sexuality of people with disabilities living in institutions. Two sample groups were used in the study comprising of eight service users (people with disabilities) and service providers from the selected institutions. Purposive and convenience sampling was employed in this study. In addition, extensive interviews and focus groups were adopted in order to validate the findings of this study. This chapter is summation of the main findings drawn from the study against the research questions raised in Chapter 1. Further, this chapter provides recommendations on how best service providers and users can work together to enhance the sexual health of people with disabilities living in institutions.

### **6.2 FINDINGS**

The core findings arising from the data analysis can be summed up as follows in respect of the institutions under study:

- Lack of sexuality policies in both the institutions;
- Lack of privacy for service users;
- Negative attitudes towards sexuality of persons with disability
- Sexual abuse was common in women with disabilities than their male counterparts;
- Lack of sexual health education programs;
- Service users' low self-esteem;
- Misconceptions about sexuality and disability in general;
- Adults with disabilities considered were as children by service providers;
- Reproduction of people with disabilities was prohibited in institutions.

Below is a brief discussion on each of these main findings using the AOP and the flower model of sexuality. Alongside this discussion, recommendations will be offered that pertain to change

regarding what can be done at the residential facilities as well as structurally to promote policy change.

### **6.3 SEXUALITY POLICY DEFICITS**

This theme is linked to the objective of establishing what sexuality policies exist in institutions as well as the challenges that people with disabilities face when it comes to sexual expression. Participants showed their unhappiness with the lack of recognition of their sexual needs. Most of the service users expressed uncertainty in terms of policies that concern dating or sexuality. Some participants did not share much on the subject which could be as a result of a lack of knowledge on the existence of any sexuality policy; however, some participants indicated that the reason why they were not in relationships was because they were not allowed to date at the residential facilities. AOP aims to assist in addressing the structural inequalities that exist. Hence, this study focused on understanding the sexuality of people with disabilities, as they are considered as an oppressed and vulnerable group (Zastrow, 2010). From the findings summarised above, it is apparent that there are policy deficits in service delivery in residential facilities when it comes to the sexuality of persons with disability.

To overcome this, there should be clear and specific guidelines around sexuality including sexual expression of people with disabilities in institutions. That way it will help individuals with disabilities to feel supported and respected. Service providers and policy developers who work in the disability sectors should develop programs and services for people with disabilities. Also, it is important for them to create and improve communication channels for people with disabilities to express themselves. This will ensure that such persons have a voice and say regarding their sexual lives.

The department of social development should ensure that residential facilities for persons with disability including private sectors have policies that represent a human rights and positive approach to sexuality. Also the department can establish a monitoring process to oversee that all organisations comply with their recommendations. The envisaged policies must provide for the training of service providers. Gomez (2012) agrees with this assertion when he highlights the importance of enforcing policies and guidelines to ensure the safety and presentation of the rights of people with disabilities in residential facilities even though policy benefits may not be immediately apparent. This will bring clarity on the parameters against which staff must get involved in the sexuality of persons with disability especially on the aspect engaging in relationships. The management in residential facilities could improve staff optimism by



providing guidelines on issues concerning sexual expression as well as potentially problematical sexual behaviour.

The quarterly disability forum meetings that service providers from residential facilities attend could have a standing item on their agenda pertaining to policy and day to day running changes and/or achievements to promote sexual expression of service users.

## **6.4 PRIVACY**

The UNCRPD (2010), Article 22 states that persons with disability have the right to privacy of information relating to their personal information as well as their health. In the present case, service users expressed their unhappiness over invasion of their privacy by service providers. Participants highlighted the following examples: sharing of rooms; sharing of bathrooms; staff getting in their rooms unannounced; and being watched or closely monitored. One of the participants also mentioned that in as much as he needed to be bathed, dressed and undressed, still, privacy was important to him despite his condition.

One of the solutions is to have separate bathrooms for males and females. In addition, it may be necessary to recruit male staff to cater for male service users and the same applies for women. The study revealed that female caregivers were uncomfortable with bathing male residents who became sexually stimulated. Regarding frustration with unannounced visits in their rooms, the researcher suggests clear routines to be laid out so that residents are aware of times when providers need to monitor or care for them to ensure that their privacy is not invaded. Service providers can schedule time tables for instance, time for laundry collection, cleaning, medication sheets in order to conserve the little privacy users have at the residential facilities. Also, staff should knock before they enter a resident's room.

People who live in institutions should have the same rights as those living in their own homes, as in actual fact these facilities are their homes. The Department of Health and Social Development advocates for normalisation of residential facilities. This entails programmes at the residential facilities being less 'institutional' and more 'homely'. This therefore means that, service users should be given the room to express themselves as normal individuals just as everyone else has the liberty to express themselves sexually when they are at home.

Residents (people with disabilities) should be given equal opportunities which allow normal development, and this applies to sexual expression as well. This means that the environment for sexual expression should be enabling and guiding and not scrutinised. Service providers,

should be non-judgmental and respectful when dealing with residents' sexual expression. They have a duty not to disregard, condemn, mock or punish people with disabilities. Service providers indicated incidents where they caught residents 'in the act', in one case a participant had to lie that she was raped for fear of being scolded and judged. This is an extreme example of the result of sexual expression being prohibited at the institutions.

## **6.5 ESTABLISHMENT OF SEXUAL HEALTH EDUCATION IN INSTITUTIONS**

This section discusses the significance of establishing and implementing sexual health education in residential facilities for persons with disabilities. The first subtheme under this theme focuses on service providers, which answers the research question of the study on the views of service providers with regards to sex education in institutions. The second section focuses on service users, there was a lack of sexual health programs for people with disabilities, and thus, much detail is afforded to recommendations.

A helpful starting point is recognising the need for such education at a governmental level whereby funding is provided for ongoing training and education. Specific recommendations are as follows:

### **6.5.1 Service Providers Training and Education**

The requirement for sexual health education should not be limited to persons with disability only but service providers and families should be trained to handle appropriately people with disabilities' expressions of sexuality. Capacity building among health professionals and disability service providers is imperative, as this may ensure a better service delivery to persons with disabilities, in terms of their sexual health. Findings showed that service providers had negative attitudes towards residents having intimate relationships especially with non-disabled people. Training is vital to improve the attitudes and awareness of service providers in order to normalise the sexuality of people with disabilities, especially intellectual disability.

The flower model of sexuality reveals the importance of service providers being equipped and empowered first, in order for them to have confidence to fully deliver their services to people with disabilities. This is because service providers need to believe that people with disabilities

have the right to intimate relationships and deserve to have good sexual health. Additionally, service providers and family members taking care of their family member with a disability, particularly adolescents, should have constant conversations with them about puberty and sexuality. If carers are educated about sexual health education they will have a better understanding and will have the know-how about imparting their knowledge to persons with disability.

This research study also highlighted that service providers were reluctant to have sexual health related conversations with their service users. Sexuality is centered to the human experience (Evans et al., 2009) hence, service providers should address the issue proactively and strike a balance between protecting persons with disability and instilling socially acceptable and appropriate behavior. The researcher suggests that staff training on sexuality starts with providers and if it cascades to their service users, then there is every reason to commence same at the inception of staff deployment, at an orientation level, at the institution. Educational programs should be age-appropriate and suitable for their mental capacity, and as the rule of thumb goes, 'talk soon, talk often' (Family Planning NSW, 2012) to encourage continuous discussion on the subject.

#### 6.5.2 Sex Education for Service Users

For a long time people with disabilities have occupied marginal positions in society and their sexuality has been considered as unimportant, yet taboo. As evidenced in the findings, service users had little knowledge about sexual health education, which is a reflection of how their sexuality was unrecognised. This problem is deep-rooted and will never be resolved without service providers accepting that persons with disability are also sexual beings who require their guidance and support.

Service users exhibited low self-esteem. Scholars like McCabe and Taleporos (2003) supports this view, that people with physical disabilities have a lower self-esteem concerning their sexuality, due to their physical appearance. Sexual health education can help persons with disability to embrace their bodies and also benefit them to have a healthy sexuality as it will boost their confidence. Sexuality education has the potential to encourage positive sexuality, encourage decision making and empower the person with intellectual disability to take

responsibility and act on their decisions. Sexual expression is an important part of being human and positive experiences can build self-esteem and a sense of identity (Adams et al., 2014).

The researcher believes that sexual health programs should be individually tailored to suit all disabilities especially people with low mental capacity. For instance, residents should be grouped according to their intellectual abilities. Low functioning people for example should be taught in a simplistic manner, using visual imagery and actual demonstrations so as to reach their level. Also, it is vital for service providers to explore other means of communication for service users to express themselves as some may have difficulties in speech. Sexual health education will also help service users to be aware of inappropriate sexual behaviour and will be able to report cases of alleged sexual assault. Also sex education can assist people with disabilities with crucial skills in social etiquette and self-care. Gomez (2012) too argues that if people with disabilities are offered information on their sexuality, they will be able to distinguish what is socially acceptable and not, when it comes to sexual expression. An example would be masturbation or sex pleasure; they will be equipped to know that it is acceptable to express themselves, but with knowledge on what is appropriate to do in private and public.

Sex education is essential as it provides people with disabilities with vast information on sexuality and it will help them to have safe and positive sexual expression as well as healthy intimate relationships. Persons with disability, predominantly those with intellectual disability, need regular socialisation with others in order for them to make friendships. This will help them to have knowledge about their sexuality including their bodies' needs. Maslow (1954) highlights that human beings need to belong and feel accepted and they have a need to love and be loved both sexually and non-sexually by others.

### 6.5.3 Improved Decision Making and Self-Protection Skills

The female participants from the study had been sexually abused at least once in their lifetime. Andersson (2010) argues that the primary sexual experience that people with disabilities have is through sexual assault. This could be true as the participants indicated that they were sexually abused at a young age. Persons with disability, particularly women are more prone to sexual abuse than the general public. Carers, whether in institutions or at home, should protect people

with disabilities by safeguarding their rights. Stringent measures should be put in place against sexual offenders.

Education has been widely recognised as a mechanism to lessen vulnerability to sexual abuse, thus young people with disabilities need to be equipped with life skills in order for them to differentiate love and abuse, appropriate and inappropriate touch and so on. This may improve their knowledge which may result in improved decision-making, especially among those with a low mental capacity. Decision-making skills are dynamic hence they can be improved through appropriate, individually designed sexuality and relationships education. Knowledge on self-protection skills can prevent an incident of abuse. Therefore, it is important for people to learn that they have the right to be safe, and are given the opportunity to learn and practice protective behaviours.

#### 6.5.4 Increased Skills for Enhanced Community Participation

With appropriate support, many people with intellectual disability can develop the necessary social skills to make healthy relationship decisions such as starting and stopping relationships, choosing whether or not to have children, and exploring sexual identity. Enhancing relationship skills will lead to more meaningful participation in their communities. Sexuality education improves a person's understanding of appropriate behaviour and builds one's capacity to participate in the community as a citizen with rights and responsibilities. The development of positive social behaviours for people with intellectual disability is therefore paramount.

## **6.6 REPRODUCTIVE HEALTH**

The majority of the service users had aspirations to have children and/ or intimate relationships; however they could not exercise this right as they are living in institutions. The majority of the service providers did not approve of sexual relationships especially since this could culminate in reproduction. Most highlighted that the institutions could not accommodate service users with children and some indicated severity of disability as the reason why they were not allowed to have children. Service providers' concerns over their residents having children were genuine considering the fact that most of the service users' disabilities were severe. The researcher understood the service providers' fears and concerns over their residents' reproductive health. There are various factors that need to be considered if a resident wants to have a child. A few

examples are the ability and capacity of the service user, availability of immediate family, medical condition of the resident and so on.

According to the United Nations Convention on the Rights of People with Disabilities there are four interrelated reproductive rights. These are: the right to equality to non-discrimination; the right to marry and find a family; the right to reproductive health including family planning and material health services; information and education; and the right to physical integrity. People with disabilities living in institutions who wish to marry and have children should be allowed to do so and be provided alternative accommodation (UNCRC, Article 23). It should be possible for service users who choose to have a family of their own or share a double room, to do so.

The researcher supports the idea that service users be given decision-making authority on what type of contraceptives are suitable for them if they wish. This also applies to those living with their families, they should be involved in deciding-making about their reproductive rights with consideration of their capacities. In extreme cases where severe mental or cognitive disability compromises one's ability to give consent then, health practitioners and services providers can intervene to evaluate the client's needs and abilities.

#### 6.6.1 Availability and Accessibility of Sexual Health Services

Some of the participants from the study were not fully aware why they were on the contraceptive injection. Their responses alternated from preventing period pains to reducing sexual drives. Legally, contraceptives should be given with consent from the person. Hence, such practices are illegal as service providers (caregivers and health professionals) have an obligation to inform and educate the clients. The researcher recommends condom use education and availability in residential facilities for adults with disabilities in order for service users to protect themselves against STIs and other venereal diseases. Also, this could help monitor sexual abuse as contraceptive injections may prevent pregnancy and yet the resident may have been abused and not reported the matter.

Information should be provided to service providers in the disability sectors in order for them to be able to teach service users topics such as puberty, contraception, reproduction and healthy relationships to support people with disabilities. This provision of information should be reflective of needs of diverse communities; this includes adolescents, adults, people with

disabilities especially those with cognitive and mental disability. Adams et al. (2014) highlights that the Flower Model of Sexuality guides service providers with materials which caters for a broad audience.

Health professionals need training to support persons with disability, thus clinics should be accessible and accommodative to everyone including wheelchair-users. According to the WPRPD (2015) accessibility is at the core of the right to human dignity, thus, service providers should ensure that there is removal of barriers and obstacles for persons with disability, to access the same services and information just like everyone else. For example, there should be provision of brail to the blind, rails and ramps for wheelchair and crutch-users - this shows inclusion and non-discrimination towards people with disabilities.

## **6.7 DECONSTRUCTION OF LABELS AND MISCONCEPTIONS**

Misconceptions regarding sexuality of people with disabilities are still dominant. Service providers from this study indicated that they believed people with disabilities are hyper sexed. Societal views towards persons with disability mould their identity and affect their self-esteem. The Social Model of Disability underlines how negative attitudes are more disabling than the impairment itself. Perceptions from service providers regarding sexuality of people with disabilities were negative and judgemental.

The reasoning behind these misconceptions was societal myths that still prevail. Likewise, service users in the study indicated that they faced barriers when it comes to expressing their sexuality at the residential facility, due to negative misconceptions. As a result, they ended up feeling embarrassed and discouraged about their sexuality.

Service providers in the disability sectors should be more open minded about sexuality and disability. There should be deconstruction of misconceptions towards people with disabilities first in order for them to offer their support and services to their clients.

The researcher believes charity begins at home, thus parents of children without disabilities can teach their children about diversity in humanity. For instance, not everyone has both legs or can see and so on. Positive attitudes could be constructed at home by parents to foster positive values in children whilst they are still young. This can also be achieved by interactions with people with disabilities for example children or youths going to volunteer at an

organisation that caters for people with disabilities. The White Paper on the Rights of People with Disabilities (2015) advocates for universal access for all children with disabilities in mainstream schools, in order for them to have equal opportunities as their non-disabled peers.

#### 6.7.1 Life-Long Children

Another misconception and labelling is on Infantilisation of adults with disabilities which needs to be addressed. Findings from the study revealed that service providers referred to service users even though they were adults as children, a phenomenon common in most adults with disabilities. Many face challenges and barriers to establishing independence in their lives socially, personal care, economically and so on, due to the fact that they are considered as children. People with disabilities should be given a fair opportunity to actually be considered as adults or make adult decisions regarding their sexuality as no one will ever let a child be engaged in any sexual activities. Thus, changing such labels will pave way for respect for privacy and expression of sexuality of persons with disabilities.

Service users should exercise dignity of risk, for them to fully enjoy their lives as sexual beings. The grey colour of the flower model of sexuality represents the dark side of sexuality. This includes exploitation, heartbreaks, manipulation and so on (Adams et al. 2014). For this purpose, people with disabilities should be given the right tools to manage their own risks, which includes getting hurt. As previously discussed, service providers felt they needed to protect their residents emotionally and physically. They felt that people with disabilities were more vulnerable than able-bodied people and that they must find partners who have disabilities as well or not date at all.

Everyone including persons with disability, has a coping mechanism, even though some with intellectual disability can deal with risks (stress or heartbreak) differently than from others; but they are capable of overcoming the problem. Hence, they should also be given the opportunity to choose partners and relationships for themselves. The researcher believes that, by allowing service users the dignity of risk, it will liberate them and give them the necessary responsibility to own their lives as adults. Also, personal empowerment can reduce vulnerability as it can enhance their abilities to safeguard themselves from risky relationships or behaviour.

This can actually be achieved if service providers refrain from regarding adult service users as children but as adults and as sexual beings just like everyone else. Anti-oppressive practices



should therefore be exercised, for example, allowing residents to have the freedom to choose what best suits them, with the guidance of their counselors, social workers or caregivers. That way, persons with disability are aware that their needs are real and that their sense of worth is significant. Policy makers and personnel in the disability sector should be involved to ensure that oppression in all levels is addressed and eradicated.

## **6.8 DISABILITY AWARENESS PROGRAMMES**

Embryonic efforts have been made to address inclusion of people with disabilities but findings from this study shows there is still a long way to go when it comes to recognition of the rights of people with disabilities. Also, stigma and discrimination were still alive in residential facilities. Article 8 of the UNCRPD states that organisations “must raise awareness of the rights, capabilities and conditions of people with disabilities”. Furthermore, organisations “must challenge stereotypes and prejudices relating to people with disabilities through, campaigning, education, media and awareness raising” campaigns (UNCRPD, Article 8).

Therefore, organisations that serve people with disabilities are required to educate the general public about disabilities to prevent discrimination, oppression, abuse, ignorance, and neglect of people with disabilities. Also, this should be complemented with awareness on disability, the aim of these programs should be to provide a comprehensive and distinguished services to everyone especially persons with disability, as the national slogan for people with disabilities says, ‘Nothing about Us without Us’. Hence, all programs regarding people with disabilities should engage them, giving voiceless and marginalised persons with disability a voice.

Respondents highlighted that they get stares, and are treated differently which is demeaning. The researcher believes if people know that disabilities are not contagious but often mostly hereditary or accidental, then maybe they can be more accepting and understanding. This can also improve their way of thinking and may result in positive attitudes towards people with disabilities.

The researcher believes that disability sensitisation is essential for better service delivery for people with disabilities as well as the general public. Constant interactions with people with disabilities and public education about disability can increase understanding and acceptance. This is evidenced in the research; volunteers who were working with people with disabilities were considered to be understanding and supportive of the service users.

Most of the service users indicated that people assume that all wheelchair-users want to be pushed or assisted of which that may not be the case all the time, thus, such assumptions can be unlearned through disability awareness. This can be achieved by educating the community, at clinics, schools, public gatherings and so on. Also, through disability sensitisation the communities are empowered with knowledge on the appropriate terminology to use to avoid offending anyone. An example is, using words such as handicapped, disabled, crippled, “these people” when referring to people with disabilities.

The researcher believes that more characters with disability the public see on television or magazines, the more they may understand disability. This may also raise awareness among the general public and it may reduce stigma and discrimination as they will be sensitised. Also, people with disabilities need to form forums with other people with disabilities for conscientisation to immunise themselves against negative attitudes.

## **6.9 RECOMMENDATIONS FOR FUTURE RESEARCH**

This study utilised a small sample of eight service users and eight service providers from one province, Gauteng in South Africa. There is need for further research with a bigger sample and in different provinces in South Africa. In-depth interviews offered the researcher valuable data. However, the researcher noted that in the focus groups, some participants were repeating what the others had said. Further research should consider the sensitive nature of the topic and use only in-depth, individual interviews.

Further research on the sexuality of persons with disability can also be conducted with those who live in their homes with families. Moreover, future research may consider looking at the reproduction of people with mental and intellectual disability, even though this study had a section on reproduction it was not fully discussed. Reproduction of persons with disability could be another avenue, as this group may have special concerns that need to be given voice contrary to public belief that oppose their reproduction. A study can be done to explore their particular needs and desires.

## 6.10 CONCLUSION

Sexuality is a fundamental aspect of the lives of all people, whether residing in residential facilities, able bodied or not. For that reason, all people should be treated with respect, irrespective of their age, sex, race, disability, mental capacity and so on.

Sexual freedom of persons with disability living in institutions does not necessarily mean they should be given ‘carte blanche’ to express their sexuality. Residential facilities have certain standards, rules and regulations that need to be considered. Also to be considered, is financial implications if children are born or medical specialists needed should there be complications to the pregnancy.

However, notwithstanding the above considerations, this study demonstrates that support from service providers that is non-judgmental and non-discriminatory will go a long way to enhancing and emancipating people with disabilities’ sexuality.

The researcher adds the following quote to support her beliefs on the subject and the findings of the study:

*“If you are not personally free to be yourself in that most human of activities ...the expression of love ...then life itself loses its meaning.”* Harvey Milk.

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## **APPENDIX 1: INFORMED CONSENT**

Dear Participant

### **RE: RESEARCH STUDY CONSENT FORM**

My name is Tapiwa Antoinette Muswera and I am a registered social worker who qualified from the University of Fort Hare with a Bachelor of Social Work degree. I am currently completing my Master of Social Work degree at the University of KwaZulu-Natal in Durban. Thank you for considering being part of this study. This letter will provide information about the research, what is it about, why is it being done and what it means for you as a participant, and if you have questions you are free to ask. This research is about, understanding sexuality of persons with disabilities at selected institutions in Gauteng. There is unclear or little information on sexuality of people with disabilities in South Africa.

The researcher will meet with you the first time to discuss with you about the consent letter, what it entails and if you agree to participate you will be given a copy of this letter you have signed. Then an appointment will be made with you for an interview at a time that is convenient for you. The interview will be conducted in either English or IsiZulu. The researcher would like to record the interview on tape (with your permission) so that she captures all the valuable information that you will share. The contents will be typed word for word however, any information that might identify you personally will be removed.

#### **Potential benefits**

There is no financial reward that you will receive for participating in this study but your contribution will help future researchers understand perceptions of sexuality from people with disabilities themselves. Through this it may help people in the community to have a better understanding of people with disabilities. As results will be disseminated to the institutions, there may well be improved services regarding the research focus. Also institutions that do not have sexuality policies for people with disabilities may reconsider their practices that are less oppressive to be more considerate and open-minded and prejudice-free when it comes to sexuality of their residents.

**Please note that the following ethics will be observed:**

1. Your participation in the study is voluntary.
2. You have the right to withdraw from the research at any stage you want.
3. There will be no rewards for participation, nor will there be any negative consequences should you decide to withdraw.
4. Strict confidentiality and anonymity will be maintained.
5. You are welcome to let the researcher know if you feel upset during or after the interview to request support.
6. If you are willing to be interviewed please indicate by ticking whether you are willing to be recorded by the following equipment:

	Willing	Not willing
Audio Equipment		
Photographic equipment		
Video equipment		

For any queries before, during and after the interview, you could contact me at 0827609146 OR notify the management at the Home for any enquiries or assistance that you might need during the interview. My supervisors are, Prof M I Kasiram at 031 260 7443 or Dr. D Hölscher at 031 260 3165.

**DECLARATION**

I..... (Full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

**SIGNATURE OF PARTICIPANT**

.....

**DATE**

.....

## APPENDIX 2: INTERVIEW SCHEDULE FOR PEOPLE WITH DISABILITIES

### PART ONE: DEMOGRAPHIC INFORMATION

**1. Age**

18-25	26-35	36-45	46-55	56+
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**2. Gender**

Male	Female
------	--------

**3. Race**

Black African	White	Asian	Coloured
---------------	-------	-------	----------

**4. Marital Status**

Married	Single	Dating	Divorced	Widowed
---------	--------	--------	----------	---------

**5. Type of disability**

Physical	Intellectual	Both
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### PART TWO: RELATIONSHIPS

1. Are you involved in a romantic relationship [do you have a boy/girlfriend]?
2. Are you allowed to date anyone at the Home?
- 3a. Have you ever been in an intimate relationship before?
- 3b. If YES, how long did it last? Did your partner have a disability?
- 3c. Tell me more about this relationship, what was challenging and good about it?
4. If you answered NO in the above questions what do you think was the reason for this?
5. What challenges do you face now when it comes to forming intimate relationships?

### PART THREE: SEXUALITY AND MYTHS ABOUT PEOPLE WITH DISABILITIES

1. What is your understanding of sexuality?
2. Who do you talk to about sex/ sexuality?
3. In your opinion what do you make of the belief that people with disabilities are oversexed?
4. How do you think people in general view people with disabilities?
5. What suggestions do you have for others with disabilities to better manage their sexual lives?



#### PART FOUR: SEX EDUCATION

1. What is your understanding of sex education?
2. What are contraceptives and have you used them before?
3. Have you been approached by someone for sex/ sexual favours?
4. If you do not want to have sex, how do you convey this to the person who is keen to have sex?
5. What aspirations do you have for family and children?
6. Do you have privacy at the Home?

## APPENDIX 3: INTERVIEW SCHEDULE FOR SERVICE PROVIDERS

### PART ONE: DEMOGRAPHIC INFORMATION

**1. Age**

18-25	26-35	36-45	46-55	56+
-------	-------	-------	-------	-----

**2. Gender**

Male	Female
------	--------

**3. Race**

Black African	White	Asian	Coloured
---------------	-------	-------	----------

**4. Marital Status**

Married	Single	Dating	Divorced	Widowed
---------	--------	--------	----------	---------

**5. Position at the Home**

Care-worker	Social worker	Manager	Other Specify
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**6. How long have you been working at the Home?**

Less than 3months	More than 5months	2-4years	5years+
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### PART TWO: RELATIONSHIPS

1. Explain the institution's policy regarding residents being allowed to have intimate relationships.
2. What is your view on whether residents should engage in intimate relationships?
3. Do you have a family member/anyone who close to you who has a disability? Tell me more about this person regarding marriage and family life.
4. What kind of relationship do you have with the residents?
5. Do the residents share their intimate information with you? Explain
6. What kind of challenges do residents face when it comes to dating?

### PART THREE: SEX EDUCATION

1. What is your understanding of sex education and its importance for those at your institution?
2. What is the institution's policy on sex education?
3. Has there been any incident of sexual abuse at the Home? Discuss
4. What do you think of the belief that people with disabilities are oversexed or asexual?
5. What are your views on whether residents be allowed to have intimate relationships with non-disabled people? Explain
6. What recommendations do you have for residents regarding expressing their sexuality?

## **APPENDIX 4: GATEKEEPER CONSENT LETTER 1**

## **APPENDIX 5: GATEKEEPER CONSENT LETTER 2**

## **APPENDIX 6: ETHICAL CLEARANCE LETTER**



P.O. Box

Tel: (011) 424-7050 Fax:

Website

06 March 2017

Dear Tapiwa

RE: PERMISSION TO CONDUCT RESEARCH AT OUR ORGANISATION

This letter serves as a confirmation that Home management committee has granted you permission to conduct your study with us. I have spoken to the residents and the staff they are keen to participate in the interviews.

Everyone is excited and eager, let me know when you can come for your appointments and consultations. I trust that all the ethical considerations stated in your consent letters will be adhered to, we wish you well in your studies.

For further assistance please do not hesitate to contact the office, 011 4247050/ 0844505089.

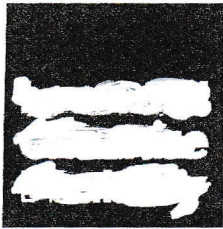
Yours in service for people with disabilities

: Home Manager

PO Box  
Putfontein,  
Tel/Fax

SA





PBO No.

PO Box  
Randburg

Tel:

Fax:

Email:  
Website:

3 March 2017

### **CONSENT LETTER FOR RESEARCH STUDY FOR TAPIWA MUSWERA**

Dear Tapiwa,

This letter serves to confirm that [redacted] Management has granted you the permission to conduct your research in the institution. All the stakeholders have been consulted and are all happy to participate in the research study.

The [redacted] management are looking forward to working with you during the study and will give you any kind of assistance you might require during the whole process.

For further assistance, please do not hesitate to call me.

Yours Faithfully,

MANAGER.



03 July 2017

**Ms Tapiwa Antoinette Muswera (215081530)**  
**School of Applied Human Sciences – Social Work**  
**Howard College Campus**

Dear Ms Muswera,

**Protocol reference number : HSS/1695/015M**

**Project title:** Understanding sexuality of persons with disabilities in institutions in Gauteng : Perspectives of persons with disabilities and service providers

**Approval Notification – Full Committee Reviewed Protocol**

With regards to your response received on 19 April 2017 to our letter of 01 December 2015, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

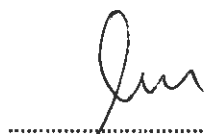
**Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.**

**PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.**

**The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.**

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully



.....  
**Dr Shenuka Singh (Chair)**

/ms

cc Supervisor: Professor MI Kasiram and Ms D Holscher  
cc Academic Leader Research: Dr Jean Steyn  
cc School Administrator: Ms Ayanda Ntuli / Mr Mike Eley

---

**Humanities & Social Sciences Research Ethics Committee**

**Dr Shenuka Singh (Chair)**

**Westville Campus, Govan Mbeki Building**

**Postal Address: Private Bag X54001, Durban 4000**

**Telephone: +27 (0) 31 260 3587/8350/4557 Facsimile: +27 (0) 31 260 4609 Email: [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za) / [snymanm@ukzn.ac.za](mailto:snymanm@ukzn.ac.za) / [mohunp@ukzn.ac.za](mailto:mohunp@ukzn.ac.za)**

**Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)**

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